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**An evaluation of factors that contribute
to late referral of cancer patients by oncologists
to hospice services in the Western Cape**

February 2011

University of Cape Town

**An evaluation of factors that contribute
to late referral of cancer patients by
oncologists and doctors working in oncology
to hospice services in the Western Cape**

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DECLARATION

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Date

University of Cape Town

*To Lukas and Ria Swart
For what you have taught me
- in living and in dying*

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MTS

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ABSTRACT

Objectives: A survey was done in the City of Cape Town Health District to identify possible barriers and other factors that influence the referral of patient to hospice by oncologists.

Methods: A self-administered questionnaire was used to explore the knowledge, attitude, belief and practice of doctors working in oncology.

Results: The majority of all doctors who took part in the survey answered the knowledge and attitude questions correctly, but it was interesting to see that nearly half of the doctors did not view discussing and treating social and spiritual problems as part of their role as oncologists.

The results of the belief questions rendered expected results but less than half of the doctors felt comfortable in treating pain all the time. The majority of doctors chose the correct answers in the practice questions. However, the results showed that although referral to hospice takes place, the referral for the majority of patients were late or very late.

Factors that influenced referral of patients to hospice included lack of training of oncologists in palliative care, the view of the oncologist's individual role in the care of his patients as well as the ability to communicate comfortably with patients regarding end-of-life care.

The doctors working in oncology were knowledgeable about the services offered by hospice although fewer doctors knew that spiritual care was being offered by hospice.

Barriers to referral to hospice that were identified included a lack of training of the doctor in care for the dying, the perception of the doctor that hospice referral means giving up on the patient and difficulty in communication regarding end-of-life care.

Doctors stated that reasons for non-referral included hospice not being available in area or not accessible to patients, the perception of the doctor that he/she is giving up on the patient, previous dissatisfaction with service by hospice and not wanting to lose control of the treatment of the patient.

Patient factors included patient resistance to referral, the perception of the patient that referral to hospice means loss of hope, fear of the unknown, the patient's perception that hospice means end of life and bad memories from the patient's perspective if the patient had lost a family member.

Conclusion: In the interest of patients, late timing of referral to hospice should be addressed by improving the training of all doctors and clinic staff to identify patients early who qualify for hospice or palliative care referral. Palliative care centres and hospice should be accessible in the community, even in rural areas. Hospices and palliative care centres should also advocate for early referral and be involved in informing doctors and the public of the services that are available in the area. Information may be out in the community but is not accessed by the community. Therefore the ideal would be to implement different types of communication like printed matter, electronic newsletters, newspapers or magazines or brochures or the performing arts for both doctors and the public.

Keywords

palliative care, oncologist, referral, hospice

ABBREVIATIONS

AAHPM	American Academy of Hospice and Palliative Medicine
ADL	activities of daily living
AIDS	acquired immunodeficiency syndrome
ASCO	American Society of Clinical Oncology
CT	computer tomography
CXR	chest X-ray
DoH	Department of Health
ECOG	Eastern Cooperative Oncology Group
et al	et alii
GP	general practitioner
HIV	human immunodeficiency virus
HPCA	Hospice Palliative Care Association
HPV	human papilloma virus
HRQL	health related quality of life
KABP	knowledge attitude belief practice
MS	Microsoft
NSAIDS	non-steroidal anti-inflammatory drugs
PC	palliative care
pt	patient
QOL	quality of life
UCT	University of Cape Town
UK	United Kingdom
US	University of Stellenbosch
USA	United States of America
vs.	versus
WHO	World Health Organisation

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Chapter 1

INTRODUCTION

Death is a certainty for everyone. Society tends to shy away from death, from talking about death, from thinking about death. Doctors often find it difficult to admit that their patients are dying.

Palliative care has developed over centuries to help patients, families and doctors to make sense of death and dying by offering expert care of the dying patient. Palliative care is applicable from early in the course of the illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy. However it appears that, for a number of reasons, some patients never experience the benefits of palliative care. Factors that contribute to late referral of cancer patients to hospice services are explored in this dissertation by evaluating the knowledge, attitudes beliefs and practices of oncologists in the Western Cape (see Appendix 1).

Although it is well known to many readers, it is enlightening to look at the history of palliative care through the ages.

Background

The first hospice (from the Latin *hospitium*, meaning a welcoming inn or guest chambers) was established by Era Fabiola, a Roman matron in the 4th century, who opened her home to the sick and destitute. During the Middle Ages, monasteries cared for the sick and dying. Early hospitals were frequently unwilling to admit those whom they considered incurable. In the 17th century a hospice to care specifically for the dying was developed in Lyon, France, under the direction of Mme. Jeanne Garnier.^{1,2,3} St Luke's Home for the Dying Poor was opened in 1893 by Dr. Howard Barrett. It was here that the effective regular 4-hourly dosing of oral morphine, balanced to the individual patient's needs, was introduced in 1948.²

Dame Cicely Saunders founded St. Christopher's Hospice, the first residential hospice, in London in 1967, thus ushering in the modern era of palliative care by combining compassionate care, astute clinical observation and research.^{1,4}

Palliative medicine is the medical component of palliative care – essentially, it is the science of symptom management. Oncology is the study of the biology and management of malignancies and since its inception, has had a disease-oriented approach to care.¹

Before the advent of modern science and medicine, disease was viewed as an experience. Modern medicine changed this concept of disease from an “experience” to one where disease is viewed as a “lesion” causing illness or disability. If the lesion could be cured, then it would follow that the disease could be cured.¹ As a result of continuous research and development, modern oncology has developed significantly in the last 50 years and the prospect of curing an illness and prolonging a patient's life is changing all the time.^{1,5}

The language of oncology is, by necessity, cancer and disease-oriented. Thus, tumours either regress or progress, and the effectiveness of the response to oncological intervention is assessed in terms of the relative tumour burden. In addition, death is seen as the ultimate defeat of the person by the cancer and dying may thus be viewed as the result of less than optimal management of the disease, rather than as a natural part of life. Treatment consists mostly of tumour management rather than patient management.^{1,5}

In a review article Davis suggested that the development of palliative medicine and the establishment of hospices occurred in protest against the neglect of the *experience* of disease.¹ The common goal of palliative care is not only to help people die peacefully, but to live fully until they die with their needs and potential met as fully as possible.²

Global burden of cancer

Cancer is a common cause of mortality and morbidity all over the world.

Currently, one in three people worldwide will develop cancer at some point in their lifetime. In addition, not all cancer is curable and one in five patients will die of their disease.^{6,7}

An estimated 1 437 180 new patients were diagnosed with cancer in the United States of America (USA) in 2008, and there were approximately 565 650 cancer related deaths in the USA that same year.⁸ According to statistics released by the World Health Organisation (WHO) cancer is a leading cause of death worldwide and accounted for 7.6 million deaths (around 13% of all deaths) in 2008. More than 70% of all cancer deaths occurred in low- and middle-income countries.⁹ In 2005 Watson reported that sixty percent of cancer diagnoses are made in patients over the age of 65 years.⁶ Elderly patients often have co-morbidities such as diabetes, ischaemic heart disease, hypertension and other diseases that already affect their quality of life. In addition modernisation has resulted in an increased life expectancy globally, resulting in an aging population. This in turn implies that the number of oncology patients worldwide will increase in the future.⁵ Deaths from cancer worldwide are projected to continue to rise to over 11 million in 2030.⁹

The burden of disease that can be attributable to cancer is increasing in the developing world, especially in sub-Saharan Africa.¹⁰ A study published in February 2010 in *The Lancet Oncology* found that the survival rate in Gambia was less than 22% for patients with cancer where the prognosis depended on the stage at diagnosis. Similarly, in Uganda, survival did not exceed 13% for any type of cancer, except breast cancer (46%). The overall survival rate was highest in China, South Korea, Singapore and Turkey.¹¹ Poverty is a risk factor for certain cancers particularly those linked to infections, such as hepatitis B and C, the human papilloma virus (HPV) and human immunodeficiency virus (HIV). The percentage of cancer cases and deaths in developing countries around the world is rising.¹² Despite increased efforts with regard to the prevention and early detection of cancer and HIV/AIDS worldwide, treatment for cancer, HIV/AIDS and palliative care is unavailable to most people in developing countries.

In Cape Town, the four leading causes of premature mortality are HIV/AIDS, tuberculosis, homicides and road traffic injuries. Together, these account for nearly half of all premature deaths.¹³ HIV-infected people and AIDS (acquired immunodeficiency syndrome) patients tend to develop cancer more frequently than the general population.¹⁴ A recent study by Patel compared the incidence of cancer among HIV-infected persons with the general population in the United States, between 1992 and 2003 and showed that the incidence of many types of non-AIDS defining cancers was higher among HIV-infected patients than in the general population. These cancers included Hodgkin's lymphoma, melanoma and leukaemia, as well as cancer of the liver, lung, anus, vagina, oropharynx, colon, rectum and kidney.¹⁵ It is reasonable to expect that these trends will develop in the HIV population in the developing world.

HIV/AIDS continues to consume many resources and the cancer burden has continued to grow, albeit without any significant increase in resources spent on cancer care. The need for palliative care is expected to increase in the developing world in response to the increasing incidence of cancer, HIV and HIV associated malignancies, especially as survival rates in resource poor countries have been showed to be lower.¹¹ In addition, the poor suffer greater disease related morbidity and mortality and have access to fewer health care goods and services.¹² This is in contrast to the availability of resources in the developed world in response to the global increase in cancer incidence.

The increase in the incidence of cancer and HIV/AIDS with poor survival rates and differences in the availability and accessibility of health care between the developing and developed countries will increase the need for palliative care especially in the developing world. Palliative care in rich countries differs from palliative care in poor countries: not only do the poor suffer greater morbidity and mortality than the rich, but they also have less access to health care goods and services.¹²

Cancer in Africa and South Africa

Patients in developing countries often present with advanced malignant disease, in fact, as many as 80% of people with cancer may already be incurable at the time of diagnosis. However, by providing access to an essential drug list of relatively cheap effective generic medications, and other methods recommended by the WHO, it was demonstrated that palliative care in the African context is affordable and achievable.¹⁶

In 2007 neoplasms were identified as the sixth leading cause of death in South Africa causing 5.8% of deaths. Cancer of the digestive, respiratory and intra-thoracic organs were amongst the leading causes of natural death in the Western Cape.¹⁷

However it has been proposed that inaccurate completion of death certificates may result in under-reporting of cancer related deaths. This has implications for national health care policy making and palliative care provision.^{18,19,20}

Although cancer patients may present late in the developing world and under-reporting may obscure a bigger problem, palliative care is affordable and can improve the quality of life of patients in the Western Cape and the rest of the world.

Definition of palliative care

Palliative care was defined by the World Health Organization (WHO) in 2002 as a holistic approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other symptoms, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients to live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance the quality of life, and will positively influence the course of the illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical symptoms.²¹

All the principles of palliative care are applicable across all age groups of patients including children.

Goals of palliative care

Some of the main objectives of palliative care are to provide impeccable assessment, holistic care and adequate pain and symptom control and to preserve and improve quality of life for all patients as best we are able to do till the end of life. However, referral to a palliative care service often comes too late to effectively improve the quality of life of cancer patients. Even if the referral is very late, the patient and family will still receive support and care even if it's only in the dying phase.

Every person has the right to expect relief from suffering, whatever its nature, whether or not its cause can be eradicated. Every person has a right to expect his or her doctor to be concerned with the quality of his or her life. All care should be patient-centered rather than pathology-centered. Palliative care is holistic care – equally concerned with physical, psychosocial, and spiritual care of each patient.⁵

Development of palliative care

In the earlier years the focus of cancer treatment was on curing the disease. Palliative care was only initiated once the decision was made that cure is not a possibility as illustrated in figure 1.

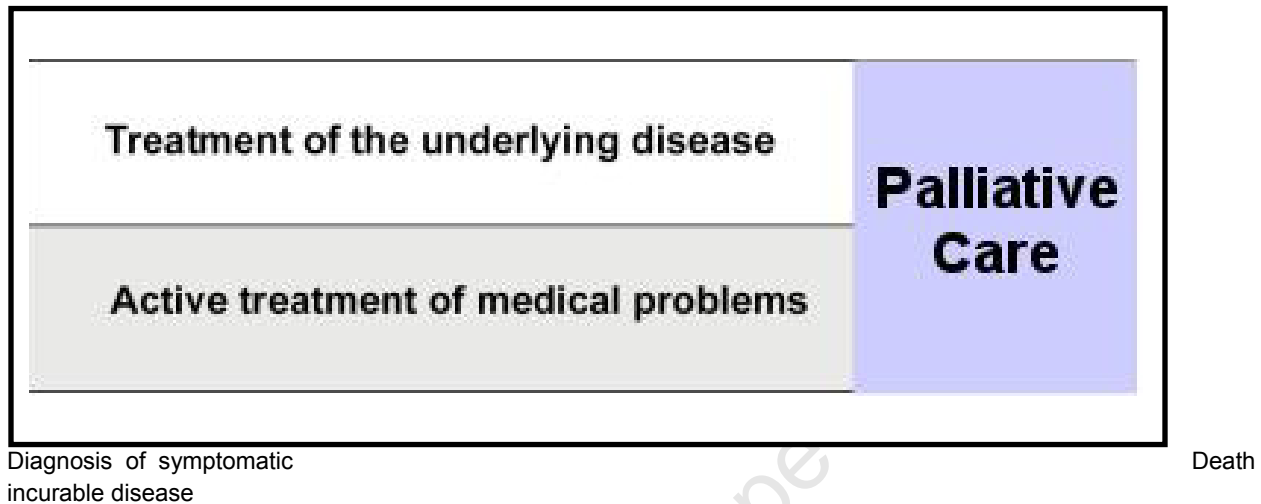


Figure1 Integration of Palliative Care into Clinical Care²²

The WHO definition of palliative care emphasizes that palliative care is applicable early in the course of the illness, in conjunction with other therapies that are implemented to prolong life.

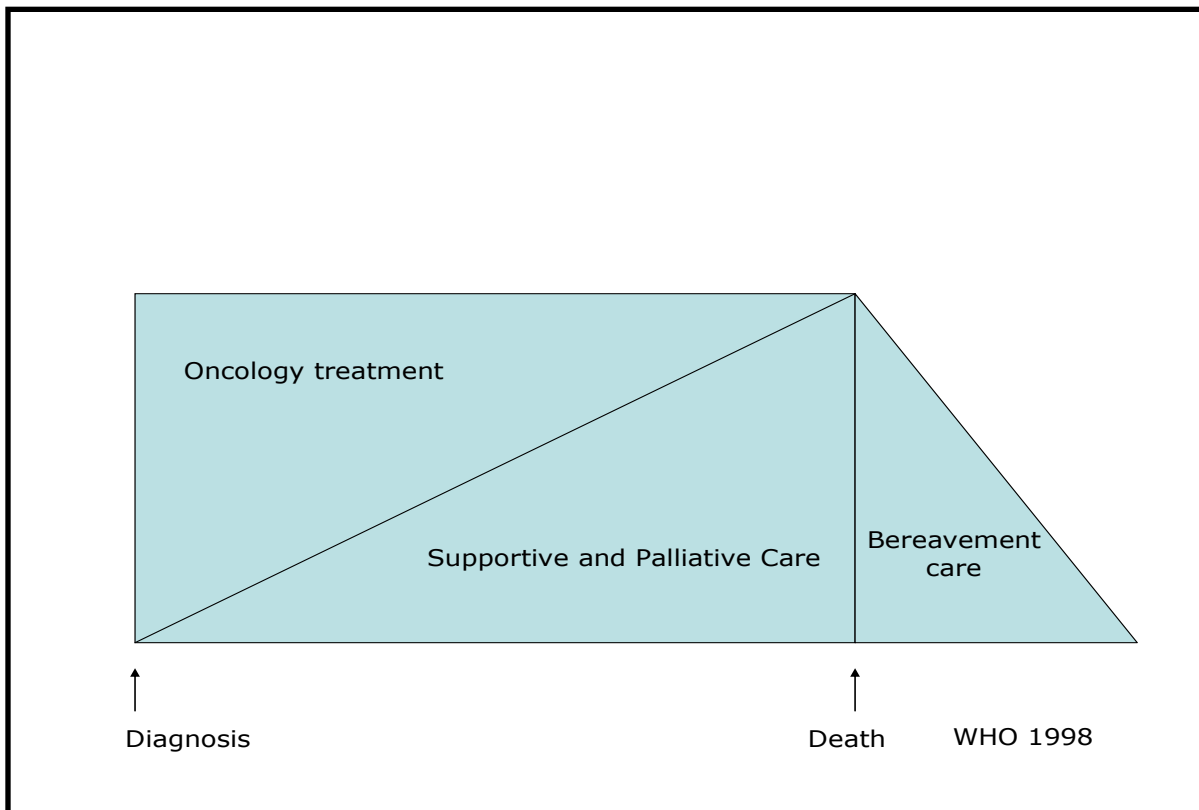


Figure 2 Continuity of Care

The WHO model, developed in 1998 and currently in use in the developed world provides for palliative care and supportive care to be offered to the patient alongside disease orientated life prolonging care (Figure 2). The care is holistic, and patient and family centred. The outcomes are better patient care, better family care and a more satisfactory professional experience for the health care provider. With more healthcare professionals training in palliative care, palliative care can be integrated earlier into the care plan of the patient. The result of early introduction of palliative care is improved quality of life for the patient and family and a dignified and peaceful death for the patient followed by better bereavement outcomes for the family.²³

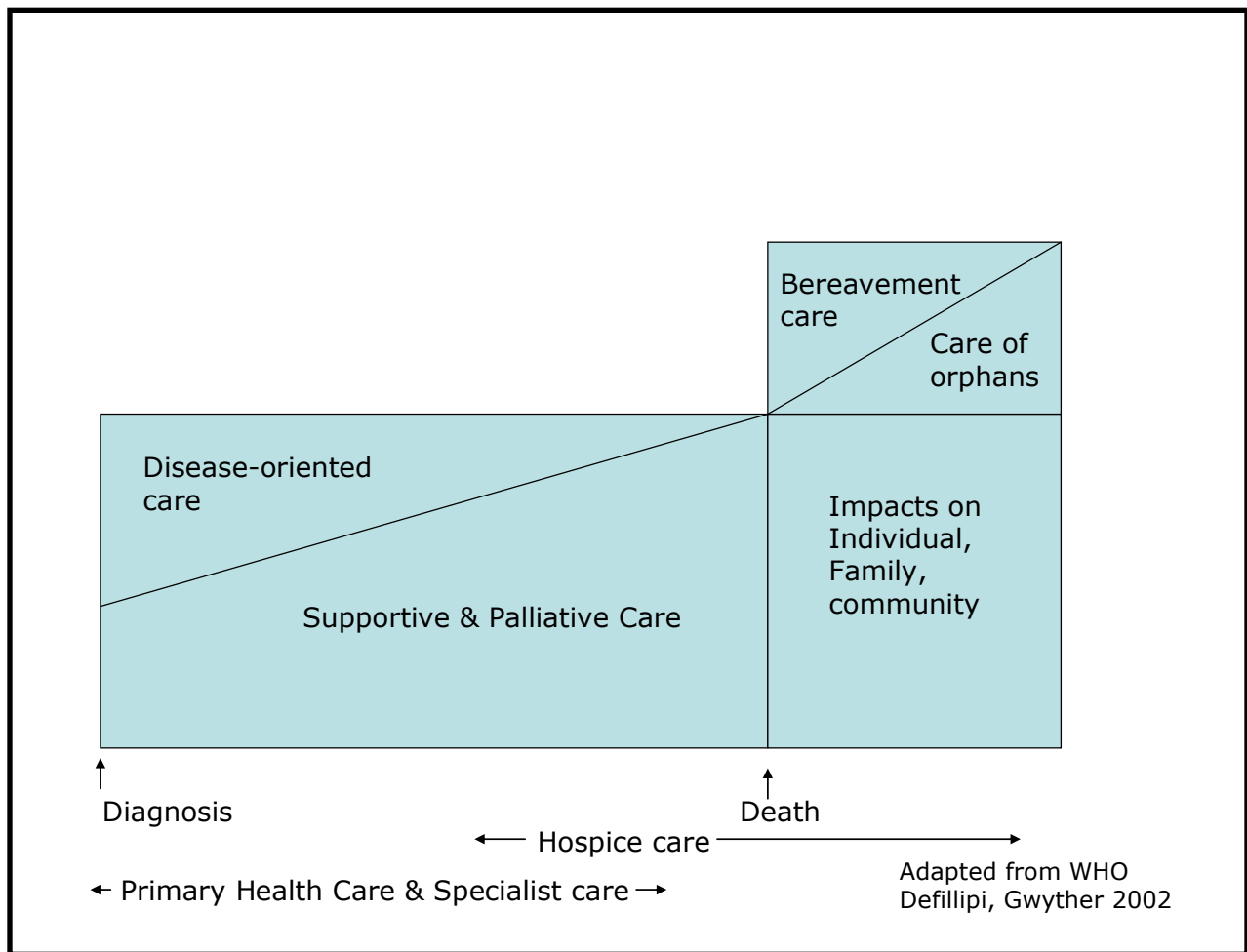


Figure 3 Continuity of Care in the Developing World

In the developing world resources are limited and fewer disease orientated treatment options are available to patients. Holistic palliative and supportive care is increasingly important for these patients. In 2002 Defillipi and Gwyther developed figure 3 from figure 2 to illustrate that with the late presentation of patients and limited resources, disease orientated care e.g. chemotherapy or radiotherapy may not be available to many patients at the time of diagnosis. Hospice care forms part of palliative care and the care to the family extends beyond the death of the patient.

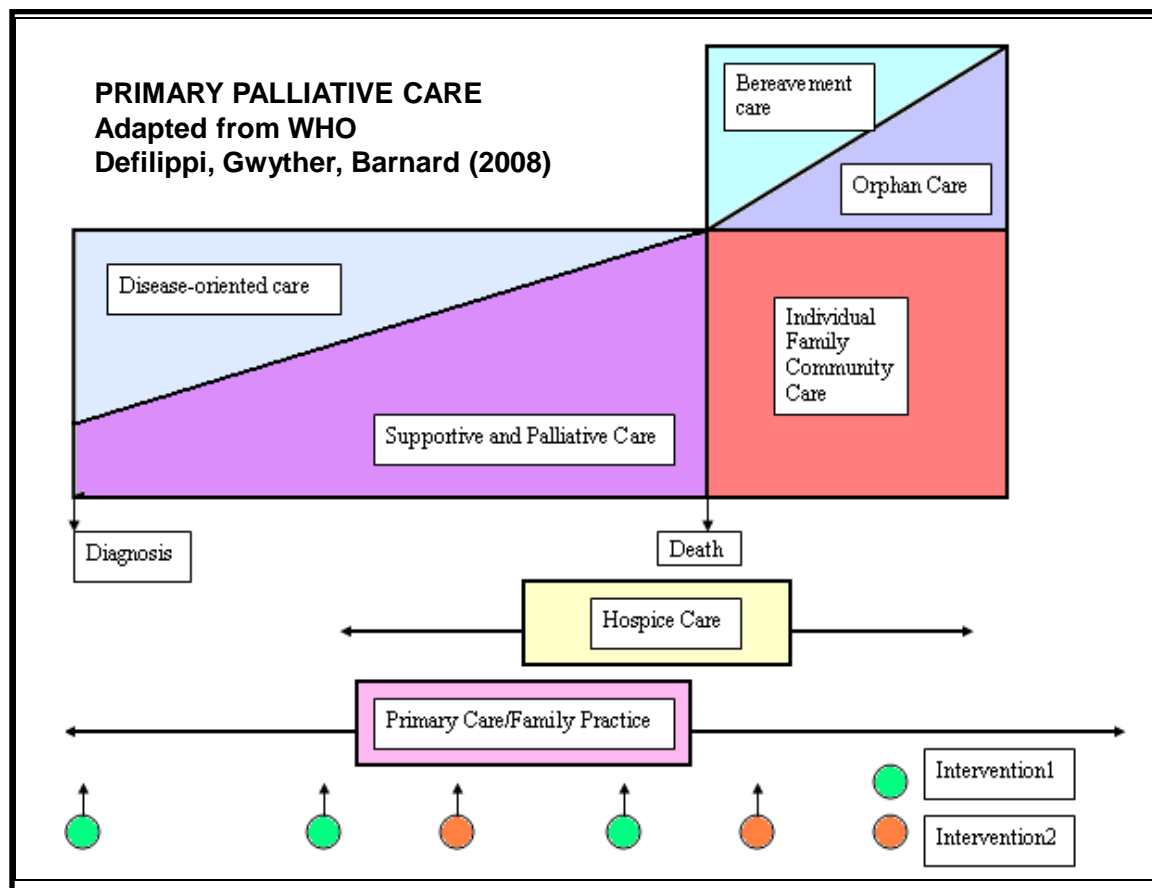


Figure 4 Primary Palliative Care ²⁴

Intervention 1 includes specialist consultations, special investigations e.g. CT, CXR.

Intervention 2 are specialist palliative care intervention

Barnard developed figure 4 from figure 3 to demonstrate the importance of primary palliative care, i.e. the value of the role of the GP/family physician or other primary care professional. The GP or primary care professional should be involved in the treatment of the patient from diagnosis, during disease orientated treatment and palliative care up to and beyond the death of the patient. The GP will continue support and treatment of the family beyond bereavement. ²⁴

Benefit of palliative care

The benefit to the patient of the holistic approach of palliative care is well researched and documented.^{4,8,25,26}

Palliative care should be initiated early on in the disease process and it should continue alongside with active anti-cancer treatment. If palliative care is instituted early in the trajectory of the disease and is used alongside conventional chemotherapy, chemotherapy can be discontinued when indicated while palliative therapy continues. In this way the patient will not experience withdrawal of chemotherapy as the withdrawal of treatment or the withdrawal of hope. Holistic palliative care by a palliative care team known to the patient and family will ensure that care is continuous until the patient dies, and will be followed by bereavement care for the family. In palliative care a patient is never abandoned.

If patients are referred to a palliative care service, like a hospice, early in the course of their disease, palliative care professionals will be able to offer both the patient and his or her family better comprehensive support in the physical, psychosocial and spiritual domains.

Patient-centered care

Every person has the right to expect relief from suffering, whatever its nature, whether or not its cause can be eradicated. Every person has a right to expect their doctors to be concerned with the quality of their life.⁵

The focus of medical care often seems to be on cure or, failing that, on life-preservation or prolongation. Palliative medicine focuses on the quality of life of a patient.⁵

Abandonment

At present many patients experience that there is a gap in care between active anticancer treatment, discontinuing of anticancer treatment and the terminal phase. Patients' needs for holistic care are not being met. The patient often experiences the feeling that the doctor is abandoning him when anticancer treatment is discontinued without palliative options being discussed.

One patient mentioned to the researcher that she felt as if “her oncologist lost interest in her” when she was not responding to the chemotherapy. Hospice and the palliative care team are trained and equipped to bridge this gap in care for patients and their families.

In a review article by Jecker and Schneiderman it was suggested that when fears of abandonment are explored, the family’s and medical team’s attention can be turned to focus on maximizing pain control, minimising suffering, address psychosocial and spiritual issues, and to prepare for death. Once denial of death is exposed and explored, it can lead to a counselling process that helps the patients and family to face and find meaning in the dying process.²⁷.

Patients may see palliative care specialists as lacking hope and referral as an indicator of impending death.¹

Holistic care

Hospice can provide holistic patient-centred care alongside oncology treatment to control distressing symptoms and help patients to live actively as possible and assist the patient to leave a legacy when they die. Dame Cicely Saunders wrote “You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

In palliative care we are caring for patients with a limited life expectancy. The palliative care team needs to assist and enable and empower patients to live life to the fullest for each day they have left on this earth. In order to do this the ideal would be to meet the patients early on in their journey with their disease. It is important to first form a trusting relationship with the patient in order to offer them and their families maximal assistance later in the trajectory of their disease. The ideal is to offer and ensure continuity of care by all the members of the palliative care team. In this way one can be certain that all aspects of the patient’s care, namely physical, psychological, social and spiritual care gets the attention it deserves.

Barriers to referral for palliative care

Medical practitioners and primary health care workers are the providers of information on palliative care to the patients. They are also the gatekeepers of referral of patients to hospice. In South Africa a patient has to be referred to hospice by a medical doctor although some hospices accept referral by clinic sisters or self-referral.

Lack of information

McGorty quotes a study by Bonham et al (1986) who found that 59% of families with terminally ill cancer patients who lived in areas served by hospices did not receive information about hospice options during the critical period of decision making. Families who were provided with hospice information by their physicians before and during their relative's terminal illness were seven times more likely to consider hospice than families who knew about hospice before the illness but did not receive any information during the illness.²⁸

Truth-telling

In a review article Fallowfield et al provided evidence from research studies that demonstrated that although the truth hurts, deceit may hurt more and they concluded that providing honest information is an ethical imperative for the truly caring clinician.²⁹

Truth-telling is of the utmost importance for patients with a limited life expectancy and is a way to promote patient autonomy.⁵ McGorty concluded the perception exists that oncologists seem to be lacking good communication skills and this can be a barrier to keeping the patient fully informed.²⁸ The patient and his family have the right to be well informed by the treating doctor regarding all the risks versus benefits and the burden of care of any proposed treatment. Cheng concluded that truth-telling is important in the care of terminally ill cancer patients especially the elderly in order to protect their autonomy and not affect their good death scores.³⁰

Communication

Medical practitioners may be reluctant to admit that cure is no longer possible or to explain that the intention of palliative chemotherapy is to gain symptom control rather than cure. This may be due to personal disappointment about the outcome, aversion to the emotional response such a conversation can engender and the fear of destroying hope.¹ Discussion may, in many cases, be eased by talking about improving quality of life, improving symptom management and prolonged life.³¹

There may be a lack of communication from the doctor's side as the disease progresses and if the implications thereof are not talked through and explained clearly to the patient and family. Doctors often have not had training in "breaking bad news" and for fear of saying the wrong thing, say nothing by default. Discussions about end-of-life care are very important but are almost always very difficult conversations to have with a patient. It is essential to plan for the end-of-life care that the patient wants, to ensure a peaceful and good death.

Communication may be impeded by a number of factors. *Doctor factors*: a high case load can put restraints on time spent in consultation and important patient cues regarding symptoms or concerns can be overlooked. Ignorance about the patient's cultural and religious background can complicate communication. *Patient factors*: Patients may feel intimidated by the oncologist's busy practice or clinic and may be paralysed by fear and anxiety reducing the effectiveness of communication with health care professionals. Patients may have the perception that the doctor is very busy and feel that asking questions will waste the doctor's time. Ethnic and cultural diversity may lead to misconceptions or even mistrust regarding treatment.³² *Illness factors*: when a patient is fatigued or confused communication may not be optimal. *Infrastructure or system factors*: Overcrowded clinics or multiple bed wards lack privacy the patient needs to discuss sensitive issues. All of the above may result in inadequate communication between doctor and patient and therefor contribute to late referral to hospice.

The patient will take courage from the reassurance given by the doctor that the latter will remain actively involved and supportive in all aspects of the terminal care of the patient.³³

A good death

Clark remarked in an editorial that we don't have good data on how people die as opposed to what they die from.³⁴ A good death has different meaning across the world. In Uganda a survey by Kikule showed a good death means the patient is cared for at home, symptom free, not experiencing stigma, at peace and his/her basic needs are being met without feeling dependant on others.³⁵ In Japan the concept of a good death included physical and psychological comfort, dying in a favourite place, maintaining a good relationship with staff, not being a burden to others, maintaining hope and pleasure amongst others.³⁶

Decision making

Health care providers should be sensitive to patient autonomy and encourage patient participation in decision making regarding treatment options and the patient's decision and choice regarding place of death. In general it appears that patients accept the decisions of their treating doctors without question. Van Tol-Geerdink reported that the desire to actively take part in decision making decreases with age and the severity of the disease such as cancer.³⁷ Patients may not have the confidence to question or challenge their doctor's decisions. It is the doctor's responsibility to educate and empower the patient to take part in these critical decisions. The patient's capacity and autonomy to choose must be promoted.^{5,38}

Futile treatment

According to a literature review by von Gruenigen and Daly, medical futility refers to treatment that serves no physiological, quantitative or qualitative meaningful purpose to the patient. They found evidence that patients continue to receive aggressive interventions, including chemotherapy, until days before their death.³⁹

In cases of advanced illness where cure is no longer possible, futile anticancer treatment is often offered and used at great financial cost to the patient, family or healthcare funders without the patient or family understanding clearly what the outcome will be. The impact on quality of life and the side effect profile can be profound.

Although the anticipated outcome may have been explained by the oncologist, patients and their families may have made different decisions regarding treatment if they had clearly understood and realised the aims and objectives and anticipated outcomes of treatment offered. The use of futile treatment that will decrease the quality of life of the patient but not alter the outcome of the disease may not be what the patient wants. In some cases a patient or the family may still choose futile treatment, but it is important to ensure that the patient has understood all the options in order to make an informed decision. Futile anti-cancer treatment should not be initiated once conventional treatment is failing the patient. Futile treatment, for example chemotherapy, may be offered even where there is no benefit to the patient in terms of curing or containing the malignancy. Futile treatment should not be initiated or continued in order to “continue doing something”, or “offering the patient further treatment”. Psychological and emotional factors may be more important factors in requesting futile treatment over and above religious, philosophical or ethical reasons. Jecker and Schneiderman raised the point that patients and families who “demand everything” are not entitled to demand miracles of the medical profession.²⁷ In addition, patients and or family members can put pressure on doctors to continue with treatment, not wanting “to give up”.⁴⁰

There are a number of reasons why doctors sometimes continue with futile curative treatment. Saunders suggested that one of these reasons may be that the treating doctor has not come to terms with his/her own mortality.⁵ Sherwin Nuland wrote “of all the professions, medicine is one of the most likely to attract people with high personal anxieties about dying. We became doctors because our ability gives us power over death of which we are so afraid. Pauline Chen wrote “... we may be a self-selected lot who eagerly suppress those fears as we adopt a professional ethos that embraces denial”.⁴¹

Many patients and families will decide against high technology and high-cost interventions when quality of life is poor. A balance should be found between individual autonomy and cost-effective healthcare. Using available resources to provide comfort and dignity for those who are dying and have a limited quality of life usually provides better care than using technology in an unsuccessful fight for survival.⁴²

Risk of treatment is magnified for patients who are facing the end of life and complications can develop. Any aggressive treatment may hasten the patient's death, which is ultimately a poor outcome.⁸

Jecker and Schneiderman commented that saying 'no' to futile treatment should not mean saying 'no' to caring for the patient. It should be the time for transferring aggressive efforts away from life prolongation toward focussing on life enhancement. Ideally "doing everything" means optimising the potential for a good life, and providing that most important coda to a good life - a "good death".²⁷

Alternative treatment

Various other treatments e.g. homeopathy, ozone therapy or herbal treatments and chemotherapy offer patients hope. Desperate patients will try anything if they have not had adequate explanation and support. Even then, patients may still choose some treatment offered. This should be respected as the patient's right to choose.

Oncologists are trained to treat cancer and they are doing what they are most skilled at and would prefer to give patients the option of oncology treatment than to withdraw treatment. If oncologists received more training in palliative care they would be skilled to offer more appropriate care and non-abandonment.

Integrating Palliative care training into Traditional medical curricula

South African doctors are all well trained in diagnosing, investigating and treating diseases and curing patients. When cure is not possible, the treating doctor may experience a sense of failing of the patient and a sense of failure in him/herself or on the part of the medical profession. The doctor may also have painful unresolved issues of personal loss.³³

Until very recently palliative care training did not form part of undergraduate training of medical doctors in South Africa. Due to the lack of training many doctors do not feel equipped to care for and assist patients at the end of life. At present some undergraduate medical students receive limited training in palliative care which has developed these skills but good palliative care should be more readily available to every patient wherever they are.

The training of undergraduate medical students and oncologists focuses strongly on curative treatment. Limited time is devoted to palliative care training. Doctors in general might therefore not feel equipped to handle end-of-life issues. Many oncologists in group practices have counselors or social workers to assist them. Driven by the need for excellent care of their patients and their sincere desire to be able to offer that care, some oncologists have developed their own palliative care skills by educating themselves. However, in general the palliative care training that oncologists receive has a narrow perspective focusing mainly on pain control, limited symptom control, palliative chemotherapy or palliative radiation rather than the comprehensive aspects of palliative care.

In April 2010 the American Academy of Hospice and Palliative Medicine published the AAHPM Position Paper: Requirements for the Successful development of Academic Palliative Care Programs. In this paper Bruera et al identified four reasons for a robust academic palliative care program in every academic medical centre which are summarised below: 1. *Clinical need* Life-expectancy is increasing and with effective treatments for many illnesses are emerging, we are confronted with growing numbers of people with chronic debilitation and life-limiting illnesses.

Palliative care uses a whole-person interdisciplinary approach to address symptom burden, complex illness and the accompanying social, psychological, spiritual and economic impact. 2. *Financial need* Palliative care has been shown to improve both the quality of care and the cost-effectiveness of care. 3. *Educational need* Many deficiencies in the quality of care experienced by the seriously ill in the USA (high symptom burden, poor doctor-patient communication, widespread fragmentation and inefficiency) can be related to a severe lack of medical and nursing education in palliative care. 4. *Research need* There is a need to evaluate efficient patient-centered care delivery systems and the Framework for Comparative effectiveness research identified palliative care as an under-researched area.⁴³

Many essential topics in medical education are, in fact, key domains of palliative care and are under-represented in both undergraduate and graduate training. Topics include pain and symptom control, psychosocial and spiritual support for the dying patient and the family, assistance with end-of-life decisions and advance care planning, continuity of care across all settings, home and hospice care, bereavement care, ethics, professionalism and interdisciplinary teamwork.⁴³

One of the recommendations from the AAHPM Position Paper is that academic medical centres should integrate palliative care at all levels to include undergraduate education, postgraduate education of residents and fellows, and continuing medical education, with financial support for faculty time necessary for curriculum and program development as well as for teaching.⁴³

Benefits of early referral

If the patient is referred early, the palliative care team will be able to provide the best possible pain and symptom control, integrate psychological, social and spiritual care for the patient and enhance and preserve quality of life for the patient until the end.

When the therapeutic index of anti-tumour therapies is limited and the benefit is outweighed by the risk or burden of the treatment, the oncologist should help to direct the patient and family to a care program that focuses on symptom palliation, and other efforts to reduce suffering, increase abilities to cope, maintain quality of life and prepare the patient and family for the end of life.⁷

Health care workers at palliative care centres are concerned by the late referrals to hospice as this limits the services and support that can be offered to the patient, family and caregivers. Timing of hospice referral may affect the benefits that patients and families derive from hospice, with early referrals increasing the benefits experienced by both patients and families.⁴⁴ Introducing hospice care in the context of a patient's goals and needs may help patients understand what services are available through hospice and limit their misconceptions like being referred because death is imminent.²⁶

Due to late referral of patients to hospice, services that can be offered are limited to assistance with crisis management, symptom control and bereavement care. Oncologists may have a limited perception of palliative care and this affects their ability to provide palliative care. Currently comprehensive palliative care is only available through hospice services in South Africa. Hospice serves only 15% of patients who needs palliative care. Palliative care is not widely available in South Africa and hospices are not available or accessible in all areas. Hospices are one of the few places that offer comprehensive palliative care in addition to the efforts of individual interested doctors and other practitioners.

Education

Progress is being made in teaching palliative care at medical schools. At University of Cape Town approximately 44 hours are spent on undergraduate palliative care training.⁴⁵ Undergraduate medical students at University of Stellenbosch receive approximately 8 hours of palliative care reference as personal communication.⁴⁶

It is of the utmost importance that palliative care education and training must be aimed at all medical practitioners and not only at oncologists in order to facilitate early referral to hospice or palliative care teams. In private health care in South Africa some types of cancer are treated primarily by specialists like surgeons/urologists/gynaecologists. Surgery and follow up is performed by the specialist without referring the patient to an oncologist. The reason for this barrier to oncologist referral is beyond the scope of this dissertation, but may be due to the fact that oncologists are not available throughout the country. However non referral also happens both in state and private hospitals in cities where oncologists are available.

Challenges encountered due to late referral

The researcher worked as a volunteer doctor at Tygerberg Hospice in the Northern Suburbs of Cape Town from March 2005 till 2008. The observation was made that the patients referred to Tygerberg Hospice for palliative care were often referred very late in the disease process. This personal experience was confirmed in discussion with colleagues at other palliative care centres.

Late referrals are a challenge for facilities and staff because health care providers are thrust into crisis management and acute-care situations without the benefits of getting to know the patient and family first.⁴⁷ This is a frustrating situation for the hospice staff as they are unable to assist the patient optimally and it may be a very traumatic experience for the patient and family. McGorty suggested that late referral may require hospice nurses to provide hyperacute death care rather than palliative care.²⁸

In practice the professional nurse receives the referral and visits the patient as soon as possible to do an initial assessment of needs. On her return some days later for a follow up visit, the nurse is then informed by the family that the patient has died. In some cases the patient was so sick and distressed on the first visit that the nurse could only assist with acute management of the crisis, uncontrolled pain or other symptoms and not be able to follow all the principles of palliative care regarding holistic care for the patient and his/her family. In these cases, the delay in referral to hospice also and most importantly meant that the patient was experiencing unnecessary suffering that could have been dealt with much earlier.

Davis remarked that late referrals mean that patients are exposed to a new care team during a crisis or transition period. This may lead to the patient experiencing increased anxiety and a sense of abandonment by the oncologist.¹

Late referral to hospice and short length of stay in hospice care are concerning because all the benefits of hospice can only be fully utilised if there is sufficient time. To provide optimal access to hospice services, conversations should occur within the context of honest prognostic disclosure, discussion of patient goals and identification of services needed.^{26,28}

Family

The patient and the family must be the unit of care. Maximizing the potential the patient and family still have for activity, relationships and reconciliation, can lead to an unique experience which may reveal hidden strengths.²

The patient's family forms an integral part of the palliative care team and needs to be part of treatment planning and be supported by the palliative care team. Receiving accurate information about the patient's condition is rated highly by family members to ensure satisfaction with the hospice service. Counseling and bereavement care is very important for family members.⁴⁸

Often the family or primary carer will acknowledge the patient's deterioration to healthcare workers but in order to protect the patient, decline referral to hospice as they do not want the patient to lose hope. Sometimes the patient declines the offer of referral to hospice in order to try and protect the family against losing hope. Patients, family members and carers avoid having difficult conversations in order to avoid painful emotions and interactions. Nieuwmeyer so eloquently calls it the "cancer silence".³³

If palliative care is used alongside curative treatment (simultaneous care) the withdrawal of curative treatment will be less traumatic to everyone and there will be continuity of care without losing hope. This approach can be described as patient centred care.⁴⁹

In a Korean cohort study of 619 patients, Yun et al concluded that family and physicians often protect patients from bad prognosis in order to give them hope for the future. Ignorance about the reality of their condition can lead to adverse outcomes for the patient such as prolonged and painful death due to unwarranted invasive care. The patient's hope may be able to be transferred from hope for cure to hope for no more suffering and feeling they are not a burden to their family as well as for a peaceful and good death.⁵⁰

These observations lead the researcher to explore the knowledge, attitudes, beliefs and practices of oncologists which contribute to referral of cancer patients to hospice. Knowledge, Attitude, Belief and Practice (KABP) surveys are based on the theory that an individual's knowledge of facts, combined with their attitudes and beliefs (including positive or negative feelings and opinions), may predict their behavior.⁵¹ The KABP survey method was chosen as the research instrument to satisfy this need and the method will be discussed later in this dissertation.

This study proposes to develop a clearer understanding of the knowledge, attitudes, beliefs and practices of oncologists and doctors working in oncology in the Western Cape regarding their referral patterns to the hospice.

Summary

The late Dame Cicely Saunders, President and Founder of St Christopher's Hospice, London so aptly puts it in the foreword to The Oxford Textbook of Palliative Medicine 3rd edition: "The increasing tendency not to tell the dying person the truth of his/her condition, the likelihood of dying in hospital, often alone, rather than at home, and the inability of the society to allow any display of emotions in public, all made death an outlaw, a forbidden subject. We have not found our way to come to terms with our mortality, and each person, each family, with little help from ritual, or tradition, or from those around, has somehow to find a way to come to terms with and grow from loss. The old acceptance of destiny has disappeared and a new sense of outrage that modern advances cannot finally halt the inevitable makes caring for the dying and for their families demanding and often difficult, but perhaps all the more rewarding as truth becomes more openly discussed"⁵

Knowledge empowers people – even people suffering or living with life threatening diseases. Holistic care of the patient includes educating the patient's family about the disease and providing training for the family members caring for the patient.

Palliative care should not be considered only as hospice care or end-of-life care and all practitioners should be skilled and equipped to offer palliative care. Early referral will enable the palliative care team members to build rapport and a relationship with the patient and his or her family that will make the difficulties that might lie ahead such as uncontrolled pain or other symptoms, death and bereavement so much easier to handle together.

It is important to raise awareness of the need for holistic comprehensive palliative care for all patients, regardless of age. Care should include emotional, spiritual and social care rather than the exclusive focus on the traditional biomedical model. All doctors including GP's, oncologists and all other medical specialists should have exposure to palliative care training and acquire the skills which only palliative care can draw together. There will always be the need for oncologists and medical practitioners with a special interest and skills in all aspects of palliative and end-of-life care including clinical, advocacy, public health, education and training to play a consulting and development role for the discipline. This will ensure improvement in both patient and family care and service delivery.

Chapter 2

Literature review

A literature review was conducted to gather information on the current thinking in oncology and palliative care considering problems that relate to the timing of referral. The literature review covered published research relating to the study topic – knowledge, attitudes, beliefs and practices of oncologists with regard to palliative care.

The literature was searched mainly electronically using Medline and Google scholar and Science Direct. Search words that were used included hospice, late referral, barriers, benefit, and palliative care. Studies that used rigorous research methods and articles that were published in peer reviewed journals were evaluated.

The literature articles were reviewed to support the need for this research and were considered in the following categories:

1. Referral issues
2. Communication
3. Clinical issues
4. Impact of palliative care on service providers
5. Integration of palliative care
6. Conclusion

1. Referral Issues

1.1 Late referral to hospice

Late referrals to hospice have a negative impact on the benefit that patients can receive from hospice.

Literature has documented that late referral to hospice was attributable to physicians wanting to avoid referring patients to palliative care “too early”.

Oncology settings echo the beliefs of “it’s not time” or “we’re not ready yet” according to an editorial by Ferrell. The National Hospice and Palliative care Organization in the United States reported in 2002 that 34.7% of those served by hospice died within 7 days of referral.⁵⁴ In a retrospective study by Cheng et al among patients treated at a comprehensive cancer centre in Houston Texas, the median time interval between the diagnosis of the primary cancer and death was 33.0 months but the median time interval between palliative care referral and death was 1.9 months.⁵⁵ In a prospective cohort study Lamont and Christakis observed the survival of 326 terminally ill cancer patients who were referred to hospice programs in Chicago. The median survival was 26 days and a number of physician factors were identified to be associated with the length of patient survival after hospice referral. Patients of physicians who referred often to hospice care survived 17 days longer when compared with patients whose physicians referred fewer patients to hospice. When a physician estimated patient survival accurately at time of referral, the patient lived 20 days longer in hospice care compared with those patients whose physicians made inaccurate survival estimates. In addition the practice specialty of the physician was found to be associated with patient survival after hospice referral. Patients referred by general internists and geriatricians lived 18 days longer in hospice care compared to patients referred by oncologists.⁵⁶ Osta et al reviewed information of 2868 patients in Texas, USA. The median time between first palliative care consult and death was 42 days. Patients with solid tumours, younger patients and female patients had earlier access to palliative care but access to palliative care at this comprehensive cancer care centre was still occurring late in the trajectory of the disease with a decrease in the interval between first palliative care consultation and death.⁵⁷ The median length of stay in hospice in the USA is approximately 3 weeks with 10% of patients enrolling in the last 24 hours of life.⁵⁸

Miceli et al noted that families rated services lower almost across the board when the referral to hospice was deemed “too late” for the patient.⁵⁹

Finlay I. noted that when considering end of life care in patients with gynaecological cancer it was impossible to diagnose the exact moment when a patient became “terminally ill”.

The patient and her family should not be deprived of the benefits of palliative care because she is not “actively dying”.⁶⁰ A mail survey with 697 respondents in the United States showed internists believed that patients should spend at least 3 months in hospice care.⁶¹

At present palliative care services are not integrated with oncology services in South Africa. Late referral means that patients may be exposed to a new care team during a crisis or transition period, increasing their anxiety and sense of abandonment by the oncologist.¹

In a prospective interview study by Kapo et al conducted in Lancaster, Pennsylvania, USA, it was stated that the national median length of stay in hospice is approximately 3 weeks and one third of patients enrol in the last week of life. When patients enrol in hospice very late, hospice providers have little time to perform assessments, establish relationships, and ameliorate common deficiencies in end-of-life care, particularly unacceptable levels of pain and suffering. Late referrals make it more difficult for hospices to provide complex services such as continuous home nursing care. At the enrolment interview 86% of patients said they believed they were enrolling in hospice at about the right time. Family members were more likely to say that enrolment was too late in the follow-up interview (17%) than they were in the enrolment interview (5%). Families who believed enrolment was too late had shorter length of stays (<3 weeks). Families perceived that hospice referral had occurred later than patients did. Patients with greater functional impairment and greater care needs perceived that hospice enrolment was occurring late. It was found that families were more likely at the second interview, one month later, to believe that hospice referral and enrolment had occurred too late. It is likely that the families' perceptions change once they had experienced the services that hospice provided and they gained a better understanding of how earlier enrolment might have been helpful. Patients and families may have lower expectations and patients and families are generally very satisfied with end-of-life care that is suboptimal by objective standards because they may not appreciate that care could have been better.⁶²

Osta et al noted that haematologic malignancies were the highest predictor of death in hospital as opposed to dying at home in hospice care as these patients have more viable treatment options that remain available despite advanced disease. Possible reasons cited were limited communication between palliative care teams and haematology oncologists as well as resistance of haematology oncologists to adopt palliative care services in their patient's care. Palliative care programs specifically targeted at the needs of patients with haematological malignancies providing needs such as blood transfusion therapy or chemotherapy have to be developed.⁵⁷

1.2 Obstacles or barriers to referral to hospice

Finlay E. et al. stated that despite increasing availability of palliative care and hospice services, there are numerous barriers to their timely use. One of the most troubling of these is the persistent association of palliative care and hospice with imminent death. For cancer patients who are seeking cure or life prolongation, and for doctors who seek to meet their patients' needs, this perception can limit the acceptance of appropriate palliative care interventions. Neither palliative care programs nor hospice are designed or restricted to those patients who are imminently dying. This idea needs to be understood by both the referring doctor and patients and family.²⁶

In a Chicago research study Daugherty examined the ethical considerations relating to the barriers preventing hospice care. It was stated that only between 20 and 50% of the half a million Americans who die annually of cancer received any formal hospice care. It was reported that although oncologists can identify patients with a life expectancy of 6 months or less, the median survival rate of cancer patients after hospice enrolment is 2-3 weeks. The report noted that this is "barely enough time for many patients and families to understand the hospice system, let alone receive the full benefit offered." Daugherty stated that "Dying of cancer without the help of a hospice program has been compared to undergoing surgery without anesthesia".⁴⁰ This is supported by Casarett's review article which identified that length of stay in hospice is approximately 3 weeks and 10% of patients enrol with the last 24 hours of their life.⁵⁸

According to Naierman general barriers to hospice referrals may include discomfort about death and grief, the sense of failure to cure, hesitation about prognosis, the perception that hospice is last resort treatment, concerns that the patient will feel abandoned and doubts that hospice offers hope to patients and families.⁶³

Meisel et al published a literature review in JAMA stating good care and ethical medical practice can be undermined by legal myths about end-of-life care. Seven myths were identified, such as if a physician prescribes or administers high doses of medication for pain relief in a terminally ill patient, resulting in death, he or she will be criminally prosecuted. It is important for doctors to be familiar with the laws of the country where they practice.⁶⁴

Financial concerns and uncertainty about hospice services also contributes to late referrals.

Patient barriers

Hyman and Bulkin and others found that patient related barriers to hospice can include the patient's belief that hospice means death, the patient's denial of terminal status, the desire to continue active treatment and the patient's lack of knowledge about hospice. The emotional frailty of a terminally ill patient, the perception that hospice means giving up or that there is no more hope may also play a role.^{28,65,66}

Physician barriers

Physician barriers to hospice use can stem from their own perceptions. Before a physician even broaches the subject of hospice with a patient and the family, the physician must firstly accept the terminality of the patient's illness, and secondly the physician has to communicate that terminality to the patient.

Buckman identified a number of fears that doctors might have that may make it more difficult to break bad news to the patient, namely fear of being blamed personally for the bad news they bring and fear of the unknown or untaught. The fear of unleashing a reaction from the patient, fear of the doctor to express emotion, fear of not knowing all the answers and a personal fear of illness and death are all factors that may complicate truthful communication with a patient.⁶⁷

Oncologists need the communication skills to cope with intense emotions of both the doctor and patient, highly distressed patients and family members with fears, anger, guilt, and anticipatory grief.⁷

Lack of knowledge of services offered by hospice, negative perceptions of hospice, lack of awareness of and experience with hospice and its benefits, fear of losing control of their patient's care and fear of malpractice are cited as barriers to referral. Prognostication can be difficult and physicians are reluctant to communicate poor prognosis to patients.^{28,40} McGorty quoted Skelly (1994) stating that the interdisciplinary approach of hospice can also be a barrier because physicians are often reluctant to share control of patient care with non-physicians. However the referring doctors have the opportunity to still be involved in the care plan as part of the multidisciplinary team. Bonham et al. (1986) found most physicians and primary caregivers view hospice as an alternative, rather as an addition, to traditional medical care.²⁸

System barriers

Casarett's review described the eligibility requirements for hospice in the United States and noted that patients must have a life expectancy of less than 6 months and must forego curative treatment. These criteria are fixed by the Medicare Hospice Benefit and are a barrier to referral. Difficulty in acceptance by patients and families that effective disease-directed treatment is no longer available or that a patient has fewer than 6 months to live poses further barriers.^{28,58} Ens et al. identified the process of referring to hospice, the lack of standardization and the lack of knowledge as barriers to referral in a study done in the Western Cape.⁶⁸

As it is clear from the literature reviewed, barriers to referral to hospice include patient, family, physician and system factors.

2. Communication

2.1 Communication re palliative care

Christakis pointed out that the better the doctor knows the patient in terms of the length and intensity of their contact, the more likely the doctor is to overestimate the patient's survival. This may explain why doctors often embark on further treatment regimens for patients who have virtually no likelihood of benefit rather than have the honest discussion about palliative care.²⁹

It almost always takes less time to explain the schedule and side effects of a new treatment regime than it does to discuss death and dying.⁴⁰

Physicians can make hospice discussions more compassionate by using skills of “breaking bad news” described in the SPIKES protocol by Buckman.⁶⁹ (see Appendix 5) The aim of a hospice discussion is to define a patient's treatment goals and needs for care and to present hospice as a way to meet those needs. Patients and families with unrealistic goals need time to readjust their plans and expectations.⁵⁸ Casarett published strategies for timely and effective hospice discussions to overcome communication barriers.⁵⁸ (see Appendix 6) Physicians are concerned that honestly disclosing a terminal prognosis to patients and family members may risk destroying hope.⁴⁰

Bruera et al investigated the attitudes and beliefs of palliative care specialists towards communication with the terminally ill. This was done via a postal survey in French speaking Europe, South America and Canada. All physicians agreed that ‘do not resuscitate’ orders should be discussed with all patients. While 93% of Canadian physicians stated that the majority of their patients would want to know about the terminal stage of their disease, only 26% of European doctors and 18% of South American doctors agreed. Almost all of the physicians said they would like to be told the truth about their own terminal illness.⁷⁰

Physicians should be encouraged to raise the subject of hospice early in the terminal disease course, so that patients can decide for themselves if and when the hospice option is right for them.²⁸

2.2 Needs of the Patient

Patients might understand the concept of end-of-life care to mean that the transition from life to death occurs peacefully and without discomfort, pain and loss of dignity.⁴

Information needs Doctors often underestimate the information needs of their patients.²⁹ In a large survey of cancer patients in the United Kingdom (UK) Jenkins et al found that 87% of the patients wanted all possible information, be it good or bad news.⁷¹

Terminal stage of illness In a multicentre prospective cohort study in Korea, published in the Journal of Clinical Oncology, Yun et al. administered validated questionnaires to 619 patients determined by physicians to be terminally ill and their family caregivers. The majority of patients (58%) and caregivers (83.4%) were aware of the patient's terminal status. Approximately 28% of patients and 23% of caregivers reported that they guessed the terminal status from the patient's worsening condition. Patients were more likely than the caregiver group to prefer that they be informed of their terminal status. Patients informed of their terminal diagnosis had a significantly better quality of life and fewer symptoms as well as a lower rate of emotional distress than patients who guessed it from their worsening condition.⁵⁰

Prognostication Physicians should admit that prognostication is uncertain, but hoping for the best is realistic. However the patient should be able to plan for the worst. Knowing how much time one has left may provide a measure of control and order in an uncertain and uncontrollable future. This will enable the patient to complete the work of dying including every person's need to feel satisfied that obligations of mending broken relationships, imparting wisdom and finishing one's business have been met.⁷²

Symptoms In a qualitative study using rigorous research methods and published in JAMA Singer et al⁷³ identified 5 factors that terminally ill patients felt were most important in their care: relief from unpleasant symptoms, avoidance of a prolonged dying process, control over care decisions, relieving loved ones of excessive burdens of care and strengthening relationships with loved ones. These domains characterizing patient's perspectives on end-of-life care, can serve as focal points for improving the quality of end-of-life care.

Hope

In her pioneering observational work about dying Kubler-Ross remarked that regardless of the stage of illness or the coping mechanisms used, patients maintained some form of hope until the last moment.⁷⁴

Destroying hope is often feared by physicians. In a descriptive article Loprinzi et al, discussed how to respond to patient queries about prognosis, and came to the conclusion that hope should not be static but rather be a dynamic entity that is reframed by circumstance, relationships, and the ongoing development of one's personal world view. This means dying patients can still hope for symptom control, resolving personal relationships, and for a dignified death.⁷²

Nuland stresses in his book that physicians should instill in dying patients the hope, not for a miraculous cure, but for the dignity and high quality of the remainder of their lives and of what they have meant, and will continue to mean, to family, friends, and colleagues.⁷⁵

Hope for cure can be redirected toward more realistic outcomes like death with dignity, death at place of patient's preference or death without excessive pain.⁴⁰ Hope for no more suffering, dying peacefully and feeling that they are not a burden to their families or carers might help terminally ill patients to cope. Physicians and families protect patients from a bad prognosis to give them hope for the future. However, not being made aware of the reality of their situation can lead to adverse outcomes for the patient such as prolonged and painful death due to unwarranted invasive therapy or dissatisfaction with the medical system.⁵⁰

Discussing end-of-life care goals

It is difficult for patients and providers to initiate end-of-life care discussions. Patients may be unclear about their priorities and may be ignorant regarding which issues could be important in their future medical care. They may also be too emotionally fragile to engage in such a discussion⁷⁶

End-of-life care planning needs to be done individually and requires focus on both medical and personal issues, taking into account the patient's culture, values and goals. Advanced directives can be difficult to interpret at times of a medical crisis, resulting in overly aggressive medical care and underutilisation of palliative care, hospice and spiritual support. Value based discussions have been demonstrated to reduce the use of non-beneficial or futile treatments, as well as result in fewer conflicts between patients and their families and reduce family anxiety.⁷⁷ Lankarani-Fard et al have used the *Go Wish* card game, developed by the Coda Alliance, as a tool in an observational study to allow patients to consider the importance of issues at the end of life in a non-confrontational environment. By sorting through their values in private, patients may present to their provider ready to have a focused conversation about end-of-life care. The value "to be free from pain" was selected by the most subjects to have the highest importance. Other highly ranked values concerned spirituality, maintaining a sense of self, symptom management, and establishing a strong relationship with health care professional. Having a tool like the *Go Wish* game may enable practitioners and patients to have a structured conversation.⁷⁶

In a review article Cherny stated that depression in cancer patients is commonly undetected or undertreated as cancer patients may believe that their emotional response is an inevitable reaction to having a cancer diagnosis. There is a perception that "good patients" do not complain and that the most distressed patients may be the least likely to acknowledge their emotional concerns.⁷

Culture

End-of-life care should cross cultural divides and care should be adapted to the patient's and family's needs. The physician and staff should respect the patient's culture and traditions.³² Care should be taken that the physician's culture, personal values and spiritual beliefs does not influence decision making.⁷⁸ Physicians need to be aware of how decisions are made, and by whom, within the patient's family system. They also should understand and be sensitive to the patient's culture and spiritual belief system.⁷⁹

Paediatric patient needs

Cancer is the leading cause of non-accidental death in childhood. The majority of children with terminal cancer die in hospital and experience substantial suffering in the last month of life. Fowler et al conducted a survey of the hospice referral practices of paediatric oncologists for children with cancer. This peer reviewed survey was developed and published in the Journal of Oncology. More respondents (86%) reported feeling comfortable managing end-of-life pain than psychological issues (67%). Many paediatric oncologists (62%) reported that half or more of their patients died in hospital. Only 2.5% of respondents referred patients to hospice at the time of a relapse. The majority referred patients when there was progressive disease, no further therapeutic options, or when death was imminent. The most common reason for non-referral was continued therapy, and was significantly higher when hospice did not admit children receiving chemotherapy.⁸⁰ Palliative care has been shown to reduce patient and parent distress by offering support to the parents while caring for the children.⁸¹

2.3 Decision making

Wagner concluded that medical decision making ideally involves a patient who has understanding of the condition and prognosis and can effectively communicate and formulate his/her preferences regarding future care. Patients with poor understanding of prognosis are less likely to discuss care preferences with family members.⁸² Honest discussion between doctor and patient is necessary to enable the patient to make informed decisions. Major decisions can be an emotional burden for the patient and family and feelings of anger, guilt and loss can be experienced.⁷⁹

Clear communication regarding the relationship between symptoms and prognosis and clinical decision making will promote understanding for patients and their families.¹ Physicians with effective communication skills can improve a patient's understanding of their illness and improve patient compliance with treatment regimens. It will also enable the physician to use time efficiently, avoid burnout and increase personal fulfillment.⁸³

The optimal timing for a discussion regarding end-of-life care is during a routine outpatient visit and not at the time of a crisis. The physician should explain the expected future disease course, potential treatment options and, together with the patient, define the goals of care prior to an acute medical crisis.⁷⁹ Conversations with the patient are often delayed if the physician has a fear of failure, causing pain and disappointment by admitting and sharing news about a negative prognosis, as well as the lack of knowledge of how to proceed with difficult conversations.⁴

The rapid functional decline that occurs in the last 3 months of life in most cancer patients are recognized by patient and health care providers as the beginning of the dying process. The patient's end-of-life goals must be identified and communicated to the family. The patient's end-of-life goals can be identified by asking directly, "What do you need or want to do in the time you have left?" The patient's psychological state can influence decision making and the physician needs to understand the patient's family value system, culture and spiritual belief system.⁷⁹

A prospective study conducted by Bruera et al exploring medical decision-making preferences of cancer patients suggested that patients more frequently preferred shared decision making than physicians predicted. Shared decision making may result in better compliance, improved patient satisfaction and better health outcomes.⁸⁴

All eventualities should be covered in end-of-life care discussions. Falk published a clinical review article, ABC of palliative care: Emergencies and stated that some acute events in patients with cancer have to be treated as an emergency to be able to reverse what is reversible and achieve a favourable outcome. Major emergencies in palliative care are hypercalcaemia, superior vena cava obstruction, spinal cord compression, bone fractures and haemorrhage. A care plan for these emergencies should be in place and although unnecessary hospital admissions can be distressing for the patient and family, missed emergency treatment of reversible conditions can be disastrous for the patient.⁸⁵ De Vader suggested that emergency practitioners should be proficient in the delivery of palliative care and that that palliative care should be initiated in emergency room when applicable.⁸⁶

Communication with patients regarding end-of-life decisions is important such as preferred place of death. Such decisions should be well documented and communicated to the family and carers. Many patients prefer to die at home. Munday et al conducted a qualitative study using semi-structured interviews of general practitioners and nurses and concluded that preferences for place of death frequently changed over time. The patients with a preference for dying at home reversed their preference if they experienced distressing symptoms, became frightened, felt vulnerable or were concerned that they had become an excessive burden to their family.⁸⁷ Decisions regarding the place of care are influenced by the nature and severity of clinical problems, the extent and availability of home-based medical and nursing care, community facilities, the goal of care and preference of the patient and family.⁷

For many patients and families the decision to decline further aggressive medical interventions represents a relief and a letting go of what has been a long struggle for continued life. It is important for the patient to know that his/her physician supports their decision and will do his/her best to honour the patient's wishes. Any treatment not contributing to the patient's goals should be discontinued.⁷⁹

From the literature it is clear that a care plan should include palliative care emergencies and advanced directives should be part of the discussion of end-of-life care.

2.4 Needs of the family

Losing a family member is a time of great sadness for families.

According to an editorial by Ferrell families supported close collaboration between oncologists and palliative care specialists, rather than a swift transfer from one provider to the other as the patient's condition declined.⁵⁴ Meyer et al showed that simultaneous care (the simultaneous delivery of investigational therapy and structured supportive care) had the benefit that progressive palliative care could be offered rather than crisis management at the end of life.⁴⁹

A truism of palliative care is that the dying patient usually knows when they are dying and that acceptance of the impending death is typically hardest not for the patient, but rather for the family. A family meeting with the consent of the patient may be helpful in providing a platform for discussion of the patient's end of life goals.⁷⁹

The needs of children or grandchildren are often overlooked. It is important to remember that for a child the loss of someone they love will have an influence on their attitude for life. Children bereaved in childhood may be vulnerable to psychiatric disorders later in life. Communication and forewarning can help children to prepare for bereavement. Children who are forewarned have lower levels of anxiety than those who are not, even in the same family. Children should also be included in rituals and attend the funeral.^{60,88}

Murray-Parkes found that effective, compassionate care in the last stages of life can bring lasting comfort to the survivors even though nothing can take away the loss itself.²

2.5 Family misconceptions

Morita et al conducted a multicentre questionnaire survey on 630 bereaved family members of cancer patients who were admitted to palliative care units in Japan. The questionnaire was validated and the article was published in The Journal of Clinical Oncology. Half of the respondents regarded the timing of referrals to palliative care units as late or very late. The families' perception regarding the appropriateness of timing of referral was influenced by inadequate communication between the treating doctor and the family, families were inadequately prepared for the deterioration in the patient's conditions or families had misconceptions about palliative care shortening the patient's life.⁴⁸

Schockett et al found that family members of patients referred too late to hospice reported lower satisfaction with hospice services, lower confidence in participating in patient care at home, more concern about coordination of care, a higher rate for unmet needs for information about what to expect at the time of death and lower overall satisfaction. Fifty percent of families reported physicians as an important barrier to hospice referral.⁸⁹ In 2007 Teno reported on research done in the USA that family member's perception of the timing of hospice referral was associated with the quality of hospice care and not with the actual length of stay in the program.⁹⁰

2.6 Physician factors that influence end-of life decisions

Various factors have been identified to influence physicians regarding end-of-life care decisions.

The physician's culture, spiritual beliefs and personal values may transcend medical knowledge, or currently accepted bioethical and legal principles. Some physicians may feel uncomfortable with the concept of withdrawing or withholding artificial feeding near the end of life, fearing that patients will die a painful death. McCann found that symptoms of hunger, thirst and dry mouth were uncommon and could easily be palliated with ice chips or small amounts of oral food.⁷⁹ A meta-analysis by Roter et al found that female physicians spent more time with patients, engaged in more active partnership behaviours, psychosocial question asking, emotionally focused talk and provided psychosocial counselling than their male colleagues.^{79,91} Cooper-Patrick et al did a telephone survey of 1816 adults at primary care practices in Washington DC, USA and found that black patients rated their visits with physicians as less participatory than white patients while patients seeing physicians of their own race rated their physician's decision-making styles as more participatory. This suggests racial differences within the physician-patient relationship and the need to improve cross-cultural communication.⁹²

Physicians may view death of a patient as a personal failure and may struggle with the issue of providing hope while trying to provide truthful information. Weissman also noted that the physician's feelings of inadequacy, guilt or family, patient or peer pressure may affect decision making.⁷⁹

In a retrospective cohort study Tang et al examined trends in the quality of end-of-life care. The results showed that cancer care tended to become increasingly aggressive in the last month of life. This was demonstrated by the intensive use of chemotherapy, frequent emergency room visits, admission to intensive care units and hospital deaths.⁹³

In a mail survey of a national sample of internists in the USA done by Christakis it was found that physicians commonly encountered situations that required prognostication, but the physicians felt poorly prepared for prognostication and found it stressful and difficult to make predictions.

They believed that patients expected too much certainty and might judge the doctor for prognostic errors. There was a wide variation in how the term “terminally ill” was interpreted.⁹⁴

The European Society of Medical Oncology surveyed its membership regarding their attitudes towards and involvement in palliative care of patients. Sixty-nine percent of respondents reported that patients with advanced cancer constituted a major proportion of their practice and for 22% it constituted most of their practice. Only 35% of respondents collaborated often with a palliative care specialist, 38% with a palliative home care service and 26% with an in-patient hospice. Respondents were involved more in palliative care clinical tasks with treating physical symptoms, such as pain, fatigue, and nausea and vomiting than in managing psychological symptoms and end-of-life care issues such as depression and anxiety. Overall, 88.4% of respondents believed that medical oncologists should coordinate the end-of-life care for their patients, but 42% felt they were inadequately trained for this task. Positive attitudes toward palliative care correlated highly with the degree of direct involvement in palliative care in practice. Fifteen percent of respondents had pervasively negative views regarding the oncologist’s role in supportive/palliative care and end-of-life care.⁹⁵

The literature supported the fact that communication factors are key to overcoming barriers to referral to hospice. There are benefits to the patient, the family and the doctor when communication is effective.

3. Clinical issues

3.1 Quality of life

Quality of life (QOL) is very important for patients in the terminal phase of their disease trajectory. Instruments to measure QOL assess the performance of activities of daily living, drug toxicity, as well as social, economic and psychological burden associated with the disease or treatment.

Validated tools are available to assess QOL and should include a patient self-assessment of symptom relief.

Patients' perceptions of QOL shift over time as patients adjust to the limitations imposed by their illnesses. Patients accept more limitations as they survive longer and rate their QOL higher than do their caregivers.¹

Optimal symptom control, psychosocial care and support, and being cared for at home in familiar surroundings can improve a patient's sense of well-being. An Australian study by Peters and Sellick has found that the most prevalent symptoms were weakness, fatigue, sleeping during the day and pain. Their results showed patients receiving home-based care had statistically significantly less symptom severity and distress, lower depression scores and better physical health and quality of life than those receiving inpatient care. Home-based care patients also reported statistically significantly more control over the effects of their illness, medical care and treatment received, and the course of the disease. The results of this study suggested that home-based care may be the preferred option for patients who are in better health, who wish to remain independent, believe they have control over the effects of their illness and treatment, and have supportive networks at home. Inpatient care in a hospice is the more likely choice for patients who are very ill, or require intensive symptom management or where the family is unable to cope with the burden of care.⁹⁶

Palliative chemotherapy and palliative radiotherapy can improve the quality of life of patients and should be used in conjunction with other palliative treatments. Most metastatic cancer in adults is incurable with antitumor therapies currently available. Patients often lose opportunities to spend their remaining time meaningfully because they are receiving marginally effective antitumor treatment. Oncologists often follow tumour response as an outcome rather than improvement in QOL or symptom relief.

Third and fourth line palliative chemotherapy regimens may be falsely assumed to have survival benefits both by the patient and oncologist.¹ Hospice referral and aggressive non-chemotherapeutic palliative measures should be considered for those patients with poorly responsive cancer (< 25 percent), low Eastern Cooperative Oncology Group (ECOG) Performance Status (PS) (see Appendix 7) or Karnofsky performance score (see Appendix 8), and poor quality of life (QOL). The ECOG Performance Status (PS) is widely used to quantify the functional status of cancer patients, and is an important factor determining prognosis in a number of malignant conditions. The PS describes the status of symptoms and functions with respect to ambulatory status and need for care.^{97,98}

Oncologists frequently state that QOL considerations lead to modification of palliative chemotherapy. In an observational study based on actual patient-physician encounters, undertaken by Detmar et al, the primary reason for modifying treatment were drug toxicity and tumour progression. Four consecutive medical consultations of 203 patients were tape-recorded and the content was analysed by three trained raters using a content checklist. For patients without evidence of tumour progression and without serious drug toxicity, but rated as having an impaired health related quality of life (HRQL), the treatments was modified or discontinued in 33% and 15% of the cases, respectively. It was found that in 20% to 54% of consultations in which patients experienced serious health related quality of life problems no time was devoted to the discussion of those problems which included fatigue and psychosocial problems. In the presence of tumour progression or serious toxicity, HRQL considerations played little or no role in treatment decision. Approximately 70% of patients with serious HRQL impairment, but without evidence of tumour progression or toxicity, continued to receive their treatment as planned. Patients themselves may be willing to accept even major limitations in their HRQL for relative small survival benefits and may have unrealistic expectations of the effect of treatment on survival.⁹⁹

In a prospective study by Puts et al reporting on the quality of life of newly diagnosed older cancer patients during the first year after diagnosis, it was shown that almost 25% of older adults (median age of 74.1) experienced clinically relevant decline in their quality of life. The decline in quality of life might be due to aging, cancer itself, the treatment, or the complications of treatment.¹⁰⁰

3.2 Symptom control

Donnelly et al conducted a comprehensive prospective analysis of symptoms of 1000 patients in which the median number of symptoms associated with advanced cancer was 11. The ten most frequent symptoms reported by patients were pain, easy fatigue, weakness, anorexia, significant weight loss, lack of energy, dry mouth, constipation, dysphagia, and early satiety. All of the above symptoms occurred in 50 percent or more of the patients taking part in the study.^{101,102} Davis reported gender differences in symptoms, severity and the type of symptoms reported by patients. Patients often underreport symptoms experienced and this leads to under-treatment and poor symptom control.¹

The use of analgesics with or without adjuvant drugs has been shown to control pain adequately in about 95% of patients with cancer pain. Pain is complex and distress from other physical symptoms and emotional, social, or spiritual anguish can influence the perception of pain. Fear is a potent modifier and fears may remain unvoiced unless their expression is directly sought by the attending professional.²⁶ Fears and misconceptions regarding the use of analgesics and more specifically morphine need to be addressed.²⁶

Despite clear WHO recommendations on analgesic use, cancer pain is still a major problem.¹⁰³ Patients who are not receiving comprehensive palliative care often suffer from uncontrolled pain or other symptoms. This has a great impact on their quality of life. Pain needs to be assessed regularly regarding the cause, site and severity and treatment regimens have to be adjusted as needed to obtain maximum pain control with minimal side effects.^{1,7}

Beck and Falkson conducted a study of 263 cancer patients and found that the prevalence of cancer pain in South Africa (30-40%) is consistent with published literature. It was found there was a significant number of cancer patients with unrelieved pain in South Africa and that 30% of cancer patients were not receiving appropriate levels of analgesics while others were receiving ineffective doses. Inpatients experienced worse pain than outpatients. It was concluded that this research likely underestimated the problem as possible communication problems including language barriers and cultural beliefs regarding pain expression might have caused under reporting. Individuals who did not have access to cancer care or services were also excluded.¹⁰⁴

Palliative pharmacological choices are based upon seven principles; one drug for multiple symptoms, the lowest possible number of drug interactions and drug side effects, drug versatility, drug efficacy, drug cost and therapeutic index.¹ Patient compliance is increased and symptom control is improved by using fewer drugs.

Spiritual or existential distress may manifest as physical or psychological problems. Pain or other symptoms unresponsive to appropriate therapy may be due to unrecognized spiritual or existential problems.²²

3.3 As death approaches

The focus of care changes in the last days of life and the family needs a clear explanation and warning that the decline appears inevitable. Sensitive nursing care is of paramount importance in ensuring that all aspects of the patient's persona are respected and dignity is maintained as he/she is dying. Any medication not concerned with maintaining comfort in the short term may be discontinued. Restlessness and other symptoms should be treated. Religious rituals and cultural requirements should be respected.⁶⁰

3.4 Patient outcomes with palliative care

Fine stated that 70 to 90 % of patients with advanced cancer have pain at the end of their lives. Nearly all patients with solid tumours have pain. In approximately 90% of people, cancer pain can be controlled through relative simple means.⁴ A literature review by Deandra et al concluded that 50% of patients with cancer pain is undertreated.¹⁰⁵ Pain control is important, firstly, because pain results in unnecessary suffering, loss of hope, rejection of active treatment and increase in depression and, secondly because uncontrolled pain prevents productive work, fulfilment of family roles and recreation. In a national survey of oncology fellows on palliative care education done by Buss et al, fellows rated attending oncologists more favourably for their oncology skills than their palliative care skills. Thus oncologists were rated as better at managing spinal cord compression than managing pain in the terminally ill patient and better at discussing chemotherapy side effects than discussing the decision to stop chemotherapy.¹⁰⁶ Hospice patients reported better outcomes in pain control in the study conducted by Beck and Falkson.¹⁰⁴

Meyers et al developed a model of Simultaneous Care whereby physicians provided both disease-directed therapy and palliative care to address more fully the physical, medical, psychosocial and spiritual needs of patients. This model provided relief of physical and emotional suffering.⁴⁹ Finlay studied several models of simultaneous oncology and palliative care. The benefits of these integrated oncology and palliative care programs include increased rates of hospice enrolment and earlier hospice utilisation, decreased emergency room visits and hospitalisation, improved quality of life and possible cost savings.²⁶

A review of 119 articles by Higginson et al was the first study to demonstrate a quantitative benefit to patients from the intervention of palliative care teams. Meta-analysis of 19 studies demonstrated a small benefit on patients' pain. Meta-regression of 26 studies found slight positive effect of palliative and hospice care teams on patient outcome with evidence of benefit the strongest for home care.¹⁰⁷

In 2010 Temel et al published in The New England Journal of Medicine the results of a randomized trial of 151 newly diagnosed metastatic non-small-cell lung cancer patients. The patients were randomized to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. The effect of palliative care was demonstrated when it was provided throughout the continuum of care for patients with advanced lung cancer. Early integration of palliative care with standard oncologic care in this group resulted in a prolonged survival of approximately 2 months and clinical improvement in mood and quality of life. It was shown that the use of health care services was altered but less aggressive end-of-life care did not adversely affect survival of these patients.³¹

3.5 Family outcomes with palliative care

Cherny commented that patients have complex care needs by virtue of increasing incapacitation and this placed stress on their families and healthcare resources. Families are often distressed and in need of support.⁹⁵ I. Finlay noted that a family must live in their grief with the memory of the patient's dying hours. The memory of a calm peaceful death appears to contribute to relatives' ability to cope in bereavement.⁶⁰ Teno reported that many people dying in institutions have unmet needs for symptom control, emotional support, physician communication and being treated with respect. Family members of patients who received home care with hospice were more likely to report a favourable dying experience.¹⁰⁸ Holistic palliative care by a multidisciplinary team will address psychosocial needs, anxiety and define personal goals. Attention to these issues will provide both patients and families with a sense of personal control and support. It will relieve caregiver burden, strengthen relationships and reduce distress for all involved.¹⁰⁹

Overcoming referral barriers and communication issues are key to the improvement of clinical issues, symptom control, QOL and to improve patient and family outcomes.

4. Impact of palliative care on service providers

4.1 Impact on doctors treating patients at end of life

Burnout

Working in oncology exposes doctors to multiple stressors, including guilt over failed treatment, existential stress over the fear of one's own death, organizational conflicts and communication problems.¹

Vachon evaluated job satisfaction among oncologists and palliative care specialists and identified four categories that determined professional satisfaction. These were dealing with patients and their families, having professional status and esteem, intellectual stimulation, and adequate resources to perform one's role. Oncologists had the lowest rating of satisfaction in all four categories but derived the greatest satisfaction from intellectual stimulation. Palliative care specialists had the highest satisfaction dealing with patients and families and adequate resources to do so.^{1,110}

Negative relationships with patients and families, dealing with dying patients, ineffective treatments, and the lack of emotional resources necessary to sustain patients and families were among items cited as creating job dissatisfaction for oncologists.¹

A study by Whippen and Canellos reported a 56% incidence of burnout in the surveyed population of randomly selected oncologists in the United States. Institution- or university-based oncologists reported a lower incidence of burnout. Frustration or a sense of failure was the most frequently chosen description of burnout and insufficient personal and/or vacation time was the most frequent reason chosen. Reimbursement issues and a heavy work load were identified as contributing factors leading to burnout.¹¹¹

Grunfeld et al conducted a survey of the prevalence of burnout, job stress and job satisfaction among cancer care workers in Ontario.

The findings supported the concern that medical oncology personnel are experiencing burnout and high levels of stress. Large numbers of these workers are considering leaving for a job outside the cancer care system or decreasing their work hours.¹¹²

A complementary relationship between oncologists and palliative care specialists can reduce stress and limit the risk for burnout, improve job satisfaction for doctors and foster improved care for patients.¹

Education needs

In the AAHPM Position paper it is stated that national surveys of medical students, residents, faculty and deans demonstrate widespread deficiencies and discomfort with basic palliative care competencies and little exposure to palliative care educational experiences.⁴³

In a national survey of practicing physicians, two-thirds stated that they felt inadequately prepared to manage chronic pain, educate patients with chronic diseases, manage psychosocial and social aspects of chronic care and provide end-of-life care.⁴³

In a 1998 survey by the American Society of Clinical Oncology (ASCO) it was found that 90% of the 3227 medical, surgical, radiation and paediatric oncologists who responded stated that they learned about palliative care through trial and error, from colleagues during clinical practice (73%), from a role model during oncology fellowship training (71%) and 38% said that a significant source of their education stemmed from a traumatic experience with a patient. Eighty-one percent of the respondents had inadequate mentoring or coaching in discussing poor prognosis; 65% said they received inadequate education about controlling symptoms; only 33% reported hearing lectures about palliative care issues during oncology fellowship training; and only 10% reported on completing a rotation on a palliative care service or hospice.^{7,113}

In a USA national survey on palliative care education among second year fellows enrolled in oncology, fellows rated attending oncologists less favourably in performing palliative care skills compared to other oncology skills.

Many fellows reported not receiving explicit education on palliative care topics: managing depression at the end-of-life (68%), opioid rotation (67%), telling a patient he/she is dying (42%) and hospice referral (37%).¹⁰⁶

A survey was done by Buss et al among physicians attending the 2004 annual meeting of the American Society of Clinical Oncology and published in the Journal of Supportive Oncology. Robust research tools were used. Only 4% of respondents answered all five knowledge questions correctly and only 31% of the fellows could calculate a simple opioid conversion correctly. The fellows surveyed in this study described inadequate quality and quantity of education about end-of-life topics and less than satisfactory mentoring and feedback when caring for patients at the end-of-life. They also demonstrated poor knowledge about basic end-of-life clinical issues and reported a relative lack of teaching about end-of-life communication, which may affect the quality and timing of end-of-life discussions with patients and families.⁴⁴

Teaching programmes has been proven to improve physicians' knowledge and have a positive change in attitudes regarding end-of-life care.¹¹⁴

Physician factors that influence end-of-life decisions.

Weissman wrote that physician factors that can influence end-of-life decisions include the physician's personal values, culture and spiritual beliefs. These factors can transcend medical knowledge. Other factors that anecdotally can influence decision making include physician's feelings that arise in the face of their patient's progressive terminal illness: inadequacy, guilt and family and peer pressure.⁷⁹

4.2 Financial implications

Yun remarked that the economic burden of disease is important in end-of-life decision making in countries such as Korea where patients pay for some or most of their medical care.⁵⁰

In 2008 Morrison published the results of a study of eight USA hospitals serving low-, medium, and high-cost markets where seriously ill patients received hospital palliative care consultation and compared this with matched patients who received usual care in the Journal of Palliative Medicine.

Hospital administrative data was used to compare hospital costs of patients receiving palliative consultation with patients receiving usual care. It was found that palliative care resulted in an adjusted net per-admission savings of \$1696 in direct costs per admission and \$279 in direct costs per day for patients discharged alive. This included significant reductions in laboratory and intensive care unit costs compared with usual care patients. The palliative care patients who died had an adjusted net savings of \$4908 in direct costs per admission and \$374 in direct costs per day, including significant reductions in pharmacy, laboratory, and intensive care unit costs compared with usual care patients.¹¹⁵

Taylor conducted a study at Duke University, Durham USA published in 2007 where a retrospective, case/control study was used to compare 1819 hospice decedents with 3638 controls matched via their predicted likelihood of dying while using a hospice. Hospice reduced Medicare program expenditures during the last year of life by an average of \$2309 per hospice user. The maximum reduction in Medicare expenditure per user was about \$7000 which occurred when a decedent had a primary condition of cancer and used a hospice for their last 58 – 103 days of life.¹¹⁶

Other studies demonstrate a dramatic decrease in hospitalizations for nursing home patients admitted to hospice, as compared to usual care. Paediatric palliative care reduces total medical costs by 15%. Any academic medical centre seeking to reduce the cost of care delivery cannot afford to overlook palliative care as an effective intervention.⁴³ It is reasonable to extend this to all medical services.

In the USA patients can only be admitted to hospice programs if the prognosis is less than 6 months.⁵⁸ This is due to funding limitations. There is now a change in this policy with discussion about “upstreaming” palliative care so that patients can spend longer time in hospice care in the USA. In South Africa, however, hospice services are non-profit organisations and strict admission criteria for prognosis do-not exist.

Barriers to referral and poor communication lead to fragmentation of services and poor outcomes for the patient, family and doctor and results in the utilization of more resources. Early referral, good communication, impeccable clinical assessment and treatment by a palliative care team that cares for the patient, ensures both good outcomes for the patient and wise use of financial resources.

5. Integrating palliative care and cancer care

Palliative chemotherapy

Many advanced cancers respond poorly to chemotherapy. Chemotherapy is associated with high side effect profile and can be costly and inconvenient to the patient. Most patients with Eastern Cooperative Oncology Group (ECOG) performance status of 2 or greater (Karnofsky score of 60) will not tolerate chemotherapy. Certain patients with ECOG score of 3 or 4 (Karnofsky score of 50 or less) should receive palliative treatment other than palliative chemotherapy.¹

Davis wrote that doctors are reluctant to explain that chemotherapy is a means of symptom control rather than cure due to personal disappointment about the outcome, aversion or inability to handle the emotional response such a conversation will engender and the fear of destroying the patient's hope. It is important to remember that chemotherapy has the potential to improve QOL unrelated to survival benefit and tumour response.¹

Chemotherapy can be used to palliate symptoms associated with advanced cancer by providing symptom relief for patients with intestinal obstruction in ovarian cancer.⁸ In selected cases chemotherapy has the potential to improve QOL unrelated to tumour response or survival benefit.¹

Palliative radiotherapy

Radiotherapy could produce local palliation for isolated and targetable disease such as treatment of rectal tumours or pain from bone metastasis. It may temporarily cause fatigue and skin reaction.^{1,8} Radiotherapy for spinal cord compression is an emergency. A short series of palliative radiotherapy for bone metastasis will give symptomatic pain relief.¹¹⁷

Integration of Palliative care in USA

In a review article Cherny noted a 2006 Best Hospital Survey of the best cancer hospitals in the United States showed that 49 of the 50 highest ranking hospitals had palliative care programs as part of their clinical services. Canada, the United Kingdom and Australia have integrated programs. However, integration of oncology and palliative care is still the exception rather than the rule in many parts of the world.⁷

A survey done in 2009 by Hui et al found that most cancer centres in the USA reported having a palliative care program but it was noted that the scope of services provided varied widely. Only twenty three percent of centres had dedicated palliative care beds while research programs and mandatory rotations for oncology fellows were uncommon.¹¹⁸

The Department of Health started palliative care training programs in hospitals in 2008 in order to facilitate accessibility of palliative care and a few private oncology practices have palliative care trained doctors on their staff.¹¹⁹

Ferris et al summarized the progress made in the United States of America in palliative care since 1998. Effective delivery of palliative care requires an interdisciplinary team that can provide palliative care in all patient settings, including outpatient clinics, acute and long-term care facilities and private homes. To integrate palliative care throughout the experience of cancer, changes in current policy, drug availability and education were recommended.¹²⁰

Integrating palliative care with primary care and oncology will better doctors' understanding of palliative care and the end-of-life needs of their patients and make doctors aware of which multi-disciplinary services are available. Meeting the needs of the patient on all levels namely physical, psychosocial and spiritual will ensure better outcomes for the patient and doctor.

6. Conclusion

Based on the studies reviewed in the literature, several factors seem to be essential to hospice utilisation. Hospice is most likely to be discussed and chosen when (i) patients acknowledge their impending death and prefer palliative care to curative measures; (ii) patients meet the requirements of hospice admission; (iii) their physicians understand the boundaries and flexibility of these requirements; (iv) physicians recognise the benefit of palliative care and do not view transfers to hospice as failure or cessation of their care. Because physicians are the gatekeepers to hospice, their discomfort in discussing hospice, death and terminal care with dying patients is a major obstacle in hospice utilisation. Physicians need to realise their considerable influence in either facilitating or hindering hospice utilisation.²⁸

Collaboration, communication, and cooperation are key to integrating oncology and palliative medicine into the best care for advanced cancer patients.¹ The integration of both tumour-directed and patient-directed care can enhance the overall quality of care of patients with advanced cancer.¹

From the literature studied, it is clear that the patient who is referred to the hospice and palliative care early in his or her disease trajectory will receive maximum benefit from the comprehensive care offered by hospice. The patient's physical, psychosocial and spiritual needs will be addressed to optimise his or her quality of life by offering maximum symptom control.¹

Having identified barriers to referral of patients to hospice in the literature, the next step would be to overcome these barriers and to facilitate closer collaboration between doctors working in oncology and hospice. This will benefit the patient, the family and the healthcare providers.

This study is going a small distance towards understanding referral patterns of doctors working in oncology in the City of Cape Town Health District, South Africa.

Chapter 3

Aims and Objectives

Aim

The aim of the study is to explore the knowledge, attitudes, practices and beliefs of oncologists in the Western Cape regarding referring patients to a hospice for inpatient or home based care.

Objectives

1. To identify the factors that influences the referral of patients to hospice services by oncologists.
2. To explore the perceptions of oncologists regarding services offered by the Hospice.
3. To identify possible barriers to early referral to hospice or palliative care services.

Chapter 4

METHODOLOGY

A survey was undertaken to explore the knowledge, attitudes, beliefs and practices of specialist oncologists and doctors working in oncology regarding referral of patients to and care of patients in a hospice in the City of Cape Town Health District (see Appendix 4).

The doctors who took part were specialist oncologists, specialist oncologists in training and medical officers with different levels of experience in oncology.

The term doctors working in oncology will be used for the purpose of this study.

STUDY DESIGN

This is a cross-sectional KABP (Knowledge, Attitude, Belief and Practice) survey and is based on the theory that individuals' knowledge (facts), combined with their attitudes and beliefs (positive or negative feelings and opinions) may predict their behaviour in general as well as in health care practice ⁵¹

SITE OF STUDY

South Africa is divided into fifty three health districts ¹¹⁹. The study was undertaken in one district, namely the City of Cape Town in the Western Cape, South Africa. The City of Cape Town covers an area of 2461km². The population in 2007 was 3.4 million ¹²⁰.

STUDY POPULATION

The total study population included all oncologists in private practice in the area as well as all doctors working in Oncology at Tygerberg Hospital in Parow and Groote Schuur Hospital in Cape Town. Tygerberg and Groote Schuur Hospitals are state facilities and are the teaching hospitals for the Universities of Stellenbosch and Cape Town.

The majority of patients consulting private oncologists are insured through a medical aid whereas non-insured patients are treated at state facilities.

SAMPLE

Cluster sampling was used and the sample consisted of all private oncologists and all doctors working in Oncology at Tygerberg Hospital. In 2006 there were 19 doctors working in oncology in private practice and 15 working in oncology at Tygerberg Hospital.

Oncologists both in private practice and in two state facilities were invited to take part in the study. One oncology unit at a state facility in Cape Town declined the invitation to take part in this study and they were excluded from the study. This limited the possible numbers of participants.

Participation was voluntary and there were no exclusion criteria. No doctors trained in palliative care took part in the study.

DATA COLLECTION

DATA COLLECTION TOOL

A questionnaire was developed to evaluate and measure the knowledge, attitudes, practices and beliefs of doctors working in oncology regarding palliative care.

In the development of the questionnaire the researcher made use of personal observation and experience as well as narratives of patients, carers, and professional nursing staff to identify areas of possible strengths and weaknesses in oncologists' knowledge, attitudes, beliefs and practices regarding palliative care and referrals to hospice care.

The questionnaire was developed by the researcher after reviewing the literature and discussion with the convenor of Palliative care at the University of Cape Town and one of the research supervisors. The questions had to be clear, unambiguous and non-leading.^{51,124}

Fakroodeen conducted a study titled *A KABP survey of pain management for advanced cancer patients amongst doctors in the Greater Durban area*. The design was similar to this study and therefore the questionnaire Fakroodeen used was reviewed. Consent was obtained and part of that questionnaire was adapted to be used in this study¹²³.

The questionnaire used in this study consisted of 25 multiple-choice questions. The number of possible responses varied. Seventeen questions had 4 possible answers, 6 questions had 5 possible answers, 1 question had 6 possible answers and 1 question had 7 possible answers.

In order to make the questionnaire both easy to use and take up the minimum time, tick boxes were used. More than one answer per question could be ticked.

Validation of data collection tool and reliability

The definition of validity consists of two aspects: the instrument must actually measure the concept in question and the measurement of the concept must be accurate. Reliability indicates the consistency or stability of the measurement¹²⁴.

Face validity was established in discussion with the research supervisors by asking if the questionnaire appeared, on consideration, to measure the variable it claims to measure.¹²⁴ Some questions were rephrased to limit ambiguity.

Pilot group

The questionnaire was piloted among six doctors to test the reliability and validity of the questionnaire. These doctors were not included in the study population. Three doctors were working in oncology at a state facility, one is a general practitioner who had completed training in palliative care and two were general practitioners enrolled in a course in palliative care.

Names and contact details of doctors who completed training in palliative care was obtained from the Department of Palliative Care at the University of Cape Town. The researcher contacted the doctors telephonically or email and the pilot was conducted by email.

Content validity

By piloting the questionnaire amongst experienced clinicians with palliative care training the researcher was able to ensure that the questions were clear, consistent and accurate. The researcher chose a group of doctors trained in the knowledge, attitudes, practice and beliefs of palliative care to ensure that the intent of the questions were clearly understood. The content of the questions had to be specific in order for the reader to understand the researcher's concern and motivation for each question. The questions had to be worded correctly to demonstrate the intent.

The completed questionnaires and data from the pilot group were reviewed to ensure that the aims and objectives of this study will be met. Changes to avoid ambiguity were made to questions where necessary after feedback from the pilot group.

DATA COLLECTION METHOD

An anonymous self-administered questionnaire was used in this study and there was no field worker to explain questions to respondents. Doctors working in adult oncology were requested to complete the questionnaire.

DISTRIBUTION OF QUESTIONNAIRE

A letter requesting permission to send the questionnaire to the oncologists at a group practice was sent to the practice or head of the department at two state hospitals.

A covering letter was presented as an introduction to this research study and to explain the objectives of this study.

An appointment was made to introduce the concept of the study to the private practice and the Head of Department of Oncology and to obtain permission to send the questionnaire to members of the practice or hospital oncologists/doctors working in oncology. This was done during a routine departmental and practice meeting in order not to take up the oncologists' time by setting up an individual appointment or an extra group meeting.

E-mail addresses were obtained for all the possible participants where possible and the questionnaire was emailed to them. This was a user friendly way to facilitate a high response rate, although postal surveys have been proven to give a better response rate than e-mail surveys.¹²⁵ According to Sheehan e-mail surveys have demonstrated superiority in terms of response speed and cost efficiency.¹²⁶

Questionnaires were delivered to oncologists' consulting rooms in the Cape Town area if e-mail addresses were unknown. All questionnaires for the doctors at the state hospital were delivered to the office of the Head of the Department. A follow up telephone call was made to the consulting rooms to ensure that the questionnaire has been received by the doctors working in oncology.

A total of 34 questionnaires were sent out to all doctors working in adult oncology, namely medical officers, registrars (specialists in training) and trained specialist oncologists at the one state facility and in private practice. No paediatric oncologists or haematology oncologists took part in the study.

On completion, these questionnaires were collected from the private practices and the state hospital by the researcher.

The timeframe for responses was one week for email questionnaires and 2 weeks for questionnaires delivered to practices after which the researcher followed up via email or telephone.

The reason for the short turnaround time is to focus the attention of the oncologist/doctor working in oncology and to get a quick response. A good response rate was important as the sample size was limited to the City of Cape Town Health District.

DATA ANALYSIS

Data was evaluated and analysed so as to be able to report the demographics of the participants, taking into account the age, sex, years of experience working in oncology, and the context of the practice or facility where oncologist work.

The questionnaire was made up of 25 multiple-choice questions which were grouped into categories of knowledge, attitude, belief and practice.

Questions relating to knowledge:	3, 5, 20, 21, 24, 25.
Questions relating to attitude:	2, 4, 10, 11, 12, 19.
Questions relating to belief:	1, 6, 14, 15, 18.
Question relating to practice:	2, 7, 8, 9, 13, 16, 17, 22.

Data was analysed with regard to questions to establish the knowledge and attitudes of oncologists/doctors working in oncology and how this impacts on the beliefs and practices of oncologists regarding palliative care.

Data was captured in MS Excel and further statistical tests were conducted with the EpiInfo package¹²⁸ as well as MedCalc¹²⁷ for the Fisher exact tests, t-test and Mann-Whitney test for independent samples.

ETHICAL CONSIDERATIONS

No patients took part or were questioned in this study.

The study was explained to the potential participants at meetings and in the covering letter sent with the questionnaire.

The covering letter invited participation and the fact that medical practitioners returned the completed questionnaire, indicated consent to participation in this research project and the use of data collected. No obligation was placed on research subjects to respond.

The questionnaire was sent to registered oncologists and doctors working in oncology only. The replies received were anonymous. The data remains anonymous and will not be traceable to an individual practitioner or practice. It will therefore not reflect on the clinical practice of a particular doctor.

ETHICAL APPROVAL TO CONDUCT THE STUDY

Approval was obtained from the research Ethics committee of Health Sciences Faculty, University of Cape Town, South Africa REC.REF256/2006. (Appendix 4)

Chapter 5

RESULTS

A total of thirty four questionnaires were sent out. Fifteen were sent to doctors in a state facility and nineteen to oncologists in private practice.

The questionnaires were distributed and received back during August 2006.

Thirty two questionnaires were received back giving a 94% response rate. This was a much higher response rate than expected. The questionnaires were analysed and the results are reported under headings of knowledge, attitudes, practice and beliefs.

Fourteen respondents were doctors in a state facility of which five were male and nine were female. Eighteen respondents were oncologists in private practice of which eleven were male and seven were female.

The average age of respondents in the state facility was 36.2 years and in private practice 47.4 years ($p=0.000122$). The mean value for years post MB.ChB. was 12.5 years for state doctors and 20.6 years for private doctors ($p<0.0001$). The mean value for years working in oncology was 7.0 years for state doctors and 18 years for private doctors ($p<0.0001$). The Fisher exact test was applied.

	State (n=14)	Private (n=18)	P-value
Male	5	11	
Female	9	7	
Average age	36.2	47.4	0.000122
Median age	35.5	46	
Range	28-45	35-67	
Years post MBChB	12.5	20.6	$p<0.0001$
Years working in oncology	7.0	18	$P<0.0001$

Table 1: Demographic analysis of participants

The overall result for each question is described in the narrative while the table and figure compare the results of state versus private. The Fisher exact test was applied to identify statistical significance in this comparison. The p values are listed in the tables. (See appendix 9 for calculations)

KNOWLEDGE

Initiating pain control

Twenty (62.5%) of the responders were using paracetamol to initiate pain control ($p=1.0000$). This is in keeping with the WHO guidelines and stepladder for pain control. {{172 Vargas-Schaffer, G. 2010}}Ten (31.3%) of the responders were using non-steroidal anti-inflammatory drugs (NSAIDS) and one (3.1%) was using morphine to initiate pain control. Ten (31.3%) respondents correctly marked the option “all of the above”.

Initiating pain control	State (n=14)	Private (n=18)
Paracetamol	9 (64.3%)	11 (61.1%) (p=1.0000)
NSAIDS	4 (28.6%)	6 (33.3%)
Morphine	0	1 (5.6%)
All of the above	5 (35.7%)	5 (27.8%)

Table 2: Initiating pain control state vs. Private

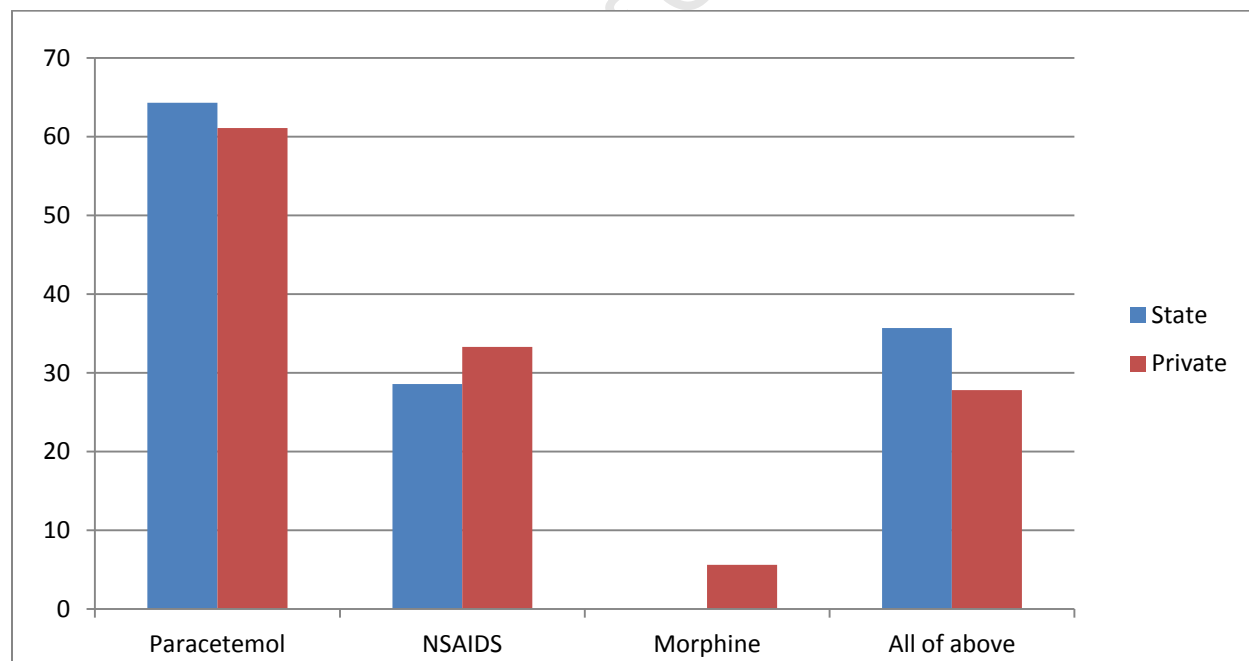


Figure 5: Initiating pain control state vs. private

Cause of pain

Six (18.8%) doctors said that pain experienced by cancer patients may be caused by the tumor. Six (18.8%) doctors said pain may be caused by the complications of cancer. Two (6.3%) doctors said pain may be caused by anti- cancer treatment. Five (15.6%) doctors said pain may be caused by conditions unrelated to cancer. Twenty nine (90.6%) doctors correctly said that pain experienced by cancer patients may be due to all of the above (p=1.00000)

Cause of pain	State (n=14)	Private (n=18)
Caused by tumour	2 (14.3%)	4 (22.2%)
Complications of cancer	2 (14.3%)	4 (22.2%)
Anticancer treatment	1 (7.1%)	1 (5.6%)
Unrelated conditions	1 (7.1%)	4 (22.2%)
All of the above	14 (100%)	15(83.3%) (p=1.00000)

Table 3: Cause of pain state vs. Private

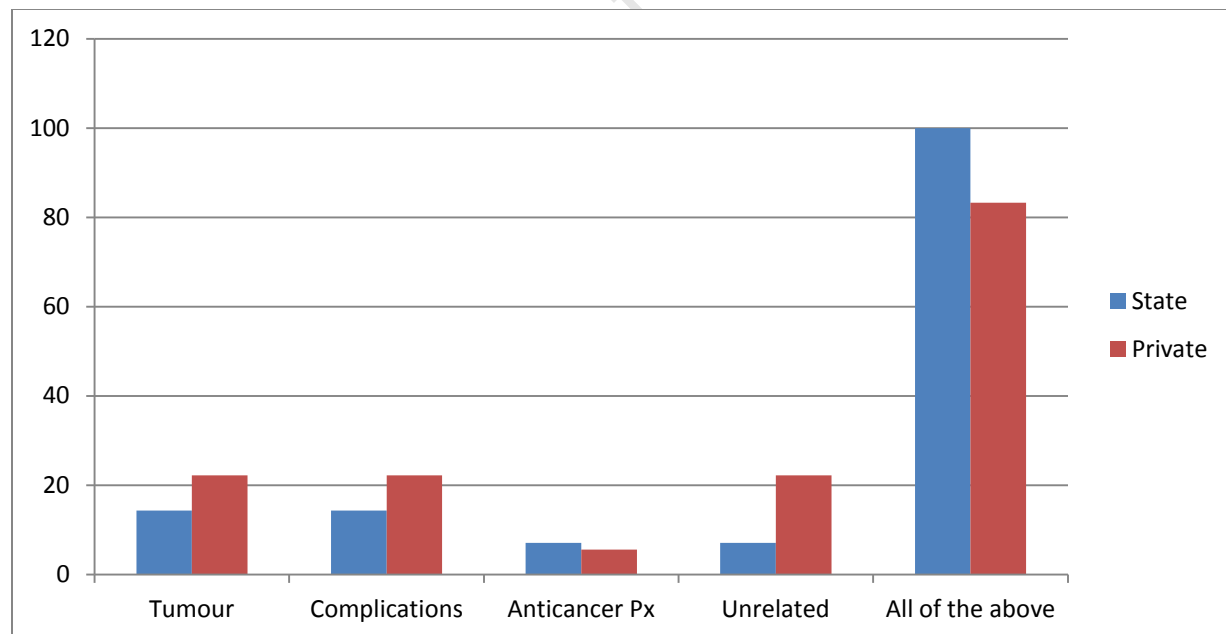


Figure 6: Cause of pain state vs. private

Benefits of private nursing

Eighteen (56.3%) doctors agreed that private nursing in the patient's home offers physical care, while twenty five (78.1%) doctors agreed private nursing in the patient's home offers assistance with activities of daily living. These two options were regarded as the correct ones. Nine (28.1%) doctors agreed that private nursing in the patient's home offers spiritual care ($p=0.453315$) while twenty (62.5%) doctors agreed that private nursing in the patient's home offers care focused on preserving quality of life. Only ten (31.3%) doctors agreed that private nursing in the patient's home offers good symptom control. This is less than expected and may be due to lack of communication regarding pain control between the private nurse practitioner and the treating doctor.

Private nursing offers	State (n=14)	Private (n=18)
Good symptom control	5 (35.7%)	5 (27.8%)
Physical care	8 (57.1%)	10 (55.6%)
Spiritual care	5 (35.7%)	4 (22.4%) ($p=0.453315$)
Assistance with ADL	11 (78.6%)	14 (77.8%)
Care focused on QOL	9 (64.3%)	11 (61.1%)

Table 4: Benefits of private nursing state vs. private

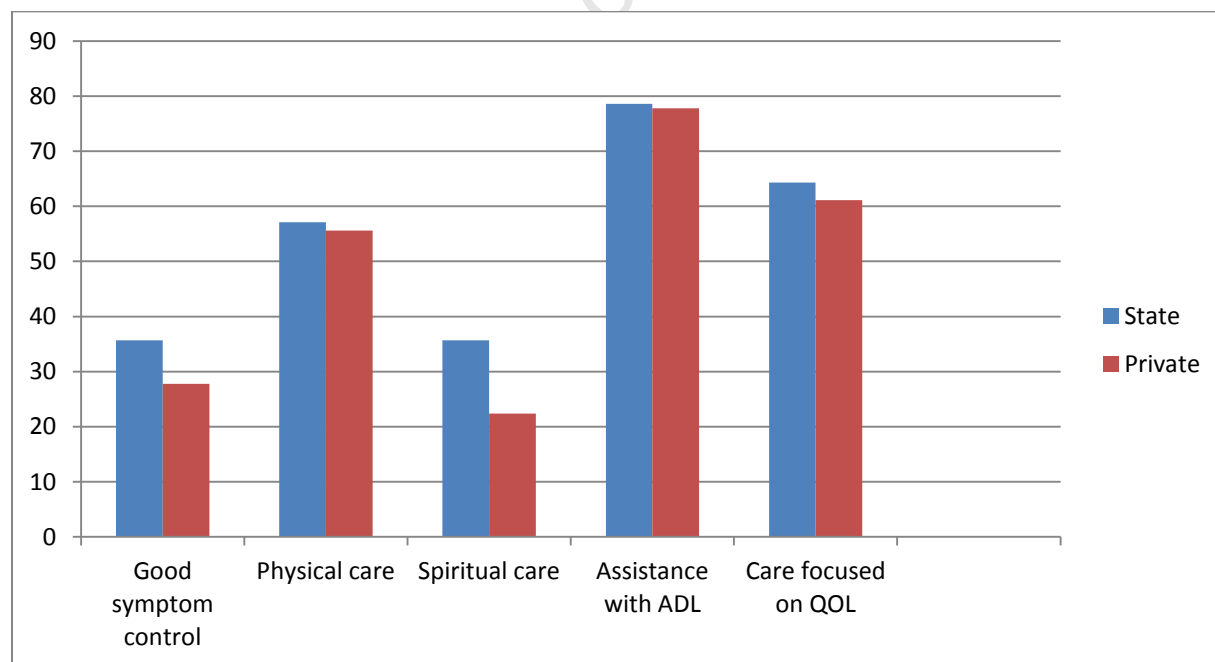


Figure 7: Benefits of private nursing state vs. private

Services offered by hospice

Thirty (93.8%) respondents said that hospice offers treatment focused on preserving quality of life during disease progression and deterioration of condition ($p=0.491935$). Twenty nine (90.6%) of respondents said that hospice offers active management of distressing symptoms. Twenty nine (90.6%) of respondents said that hospice offers psychosocial support. Twenty four (75%) of respondents said that hospice offers spiritual care. All of the above services are offered by hospice.

Hospice services	State (n=14)	Private (n=18)
Treatment focused on QOL	14 (100%)	16(88.9%) ($p=0.491935$)
Management distressing symptoms	13 (92.9%)	16 (88.9%)
Psychosocial support	11 (78.6%)	18 (100%)
Spiritual care	8 (57.1%)	16 (88.9%)

Table 5: Services offered by hospice state vs. private

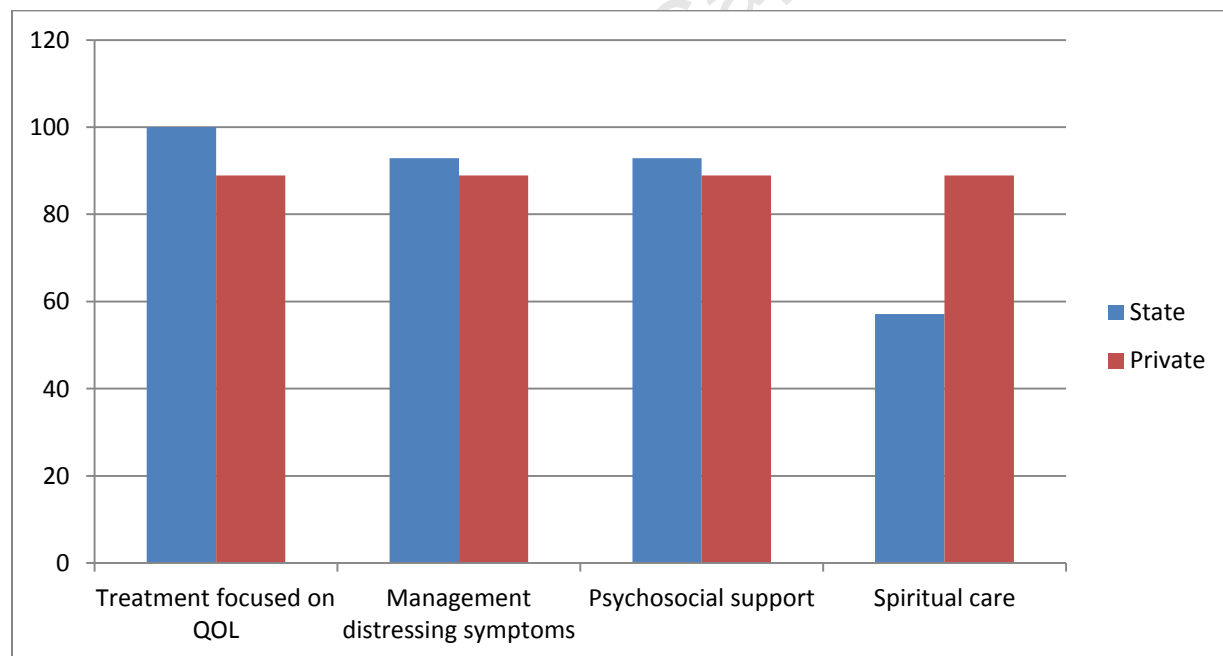


Figure 8: Hospice services state vs. private

Useful analgesic adjuvants

Six (18.8%) doctors said that non-steroidal anti-inflammatory drugs (NSAIDs) are useful analgesic adjuvants. Four (12.5%) doctors said that corticosteroids are useful analgesic adjuvants, while four (12.5%) doctors said that tricyclic antidepressants are useful analgesic adjuvants. Twenty eight (87.5%) doctors said that NSAIDs, corticosteroids and tricyclic antidepressants are all useful analgesic adjuvants (“all of the above”), which was the correct answer ($p=0.027836$).

Analgesic adjuvant	State (n=14)	Private (n=18)
NSAID	6 (42.9%)	0
Corticosteroids	4 (28.6%)	0
Tricyclic antidepressants	4 (28.6%)	0
All of the above	10 (71.4%)	18(100%) ($p=0.027836$)
None of the above	0	0

Table 6: Useful analgesic adjuvants state vs. private

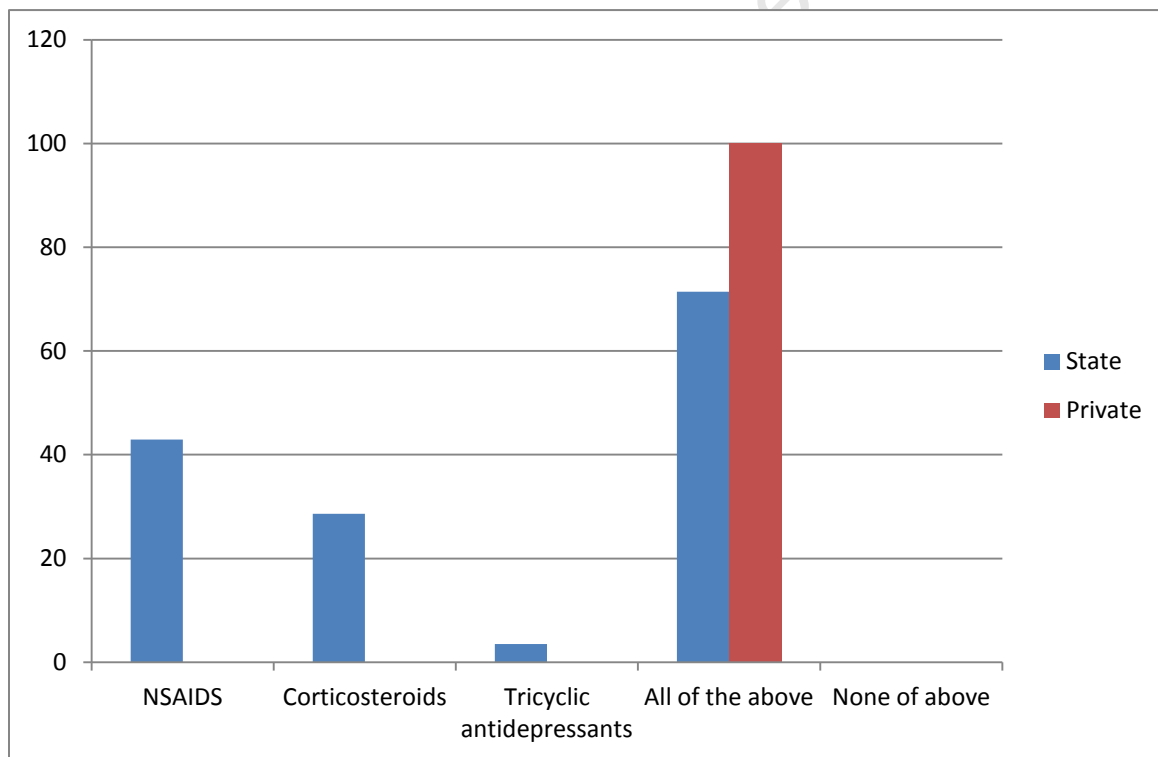


Figure 9: Analgesic adjuvants state vs. private

The understanding of palliative care

Twenty five (78.1%) doctors understood palliative care to include pain control and active symptom control. Twenty three (71.9%) doctors understood palliative care to be a holistic approach. Ten (31.3%) doctors understood palliative care to be palliative chemotherapy. Twenty two (68.8%) doctors understood palliative care to be psychosocial support ($p=0.008374$). Twenty (62.5%) doctors understood palliative care to be support to the family. Seventeen (53.1%) doctors understood palliative care to be spiritual care. Twenty two (68.8%) doctors understood palliative care to be a support system to assist the patient to live as actively as possible.

Understanding of PC	State (n=14)	Private (n=18)
Pain and symptom control	9 (64.3%)	16 (88.9%) ($p=0.194753$)
Holistic approach	8 (57.1%)	15 (83.3%) ($p=0.131657$)
Palliative chemotherapy	4 (28.6%)	6 (33.3%) ($p=1.000000$)
Psychosocial support	6 (42.9%)	16 (88.9%) ($p=0.008374$)
Support to the family	7 (50%)	13 (72.2%) ($p=0.276943$)
Spiritual care	6 (42.9%)	11 (61.1%) ($p=0.476451$)
Support system for patient	9 (64.3%)	13 (72.2%) ($p=0.711953$)

Table 7: Understanding of palliative care state vs. private

The private doctors had an overall better understanding of what palliative care is. Only 42.9% of state doctors knew that palliative care include psychosocial and spiritual care and only a third of doctors viewed palliative chemotherapy as palliative care.

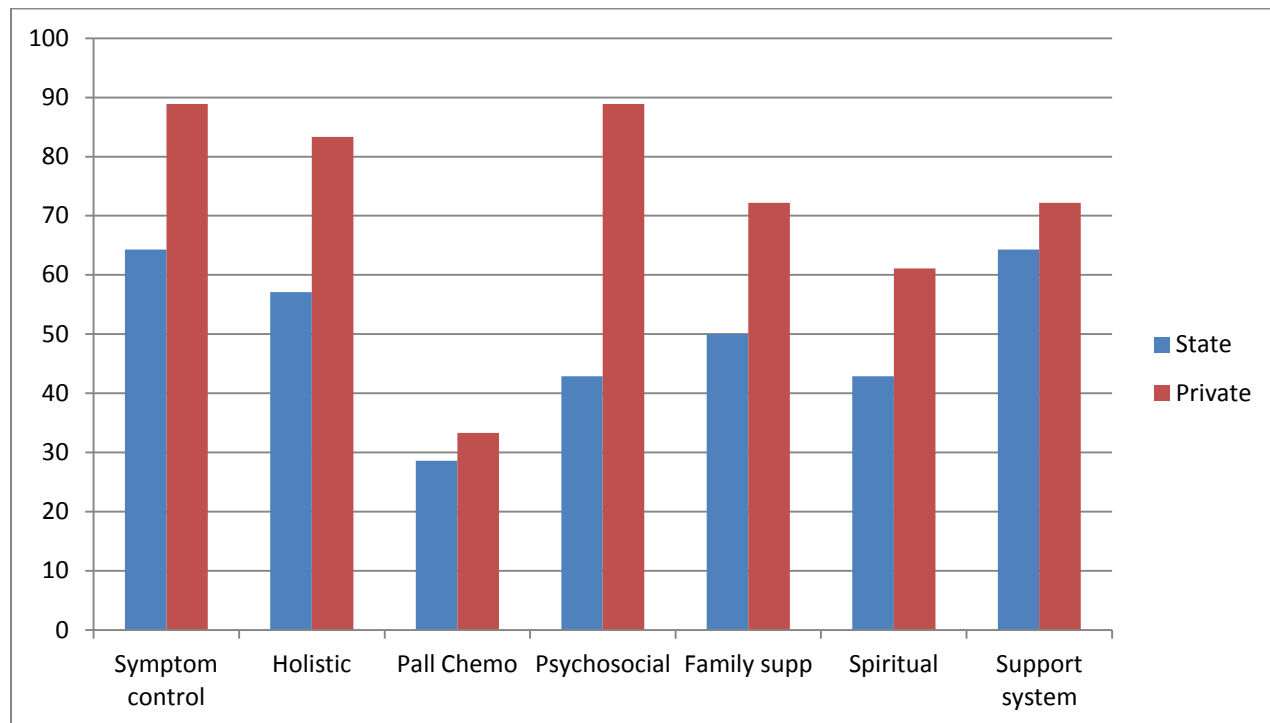


Figure 10: Understanding of palliative care state vs. private

Comment

From the above results it is clear that there is no statistical significance in reported knowledge between these 2 groups both of whom scored highly on knowledge questions.

ATTITUDE

Morphine for pain control

All thirty two (100%) of doctors correctly said they would prescribe morphine as analgesic therapy for severe pain at any time during the course of the patient's cancer.

Morphine for pain control	State (n=14)	Private (n=18)
Any time during course	14 (100%)	18 (100%)
Prognosis less than 1 year	0	0
Prognosis less than 6 months	0	0
Prognosis less than 3 months	0	0

Table 8: Use of morphine for pain control state vs. private

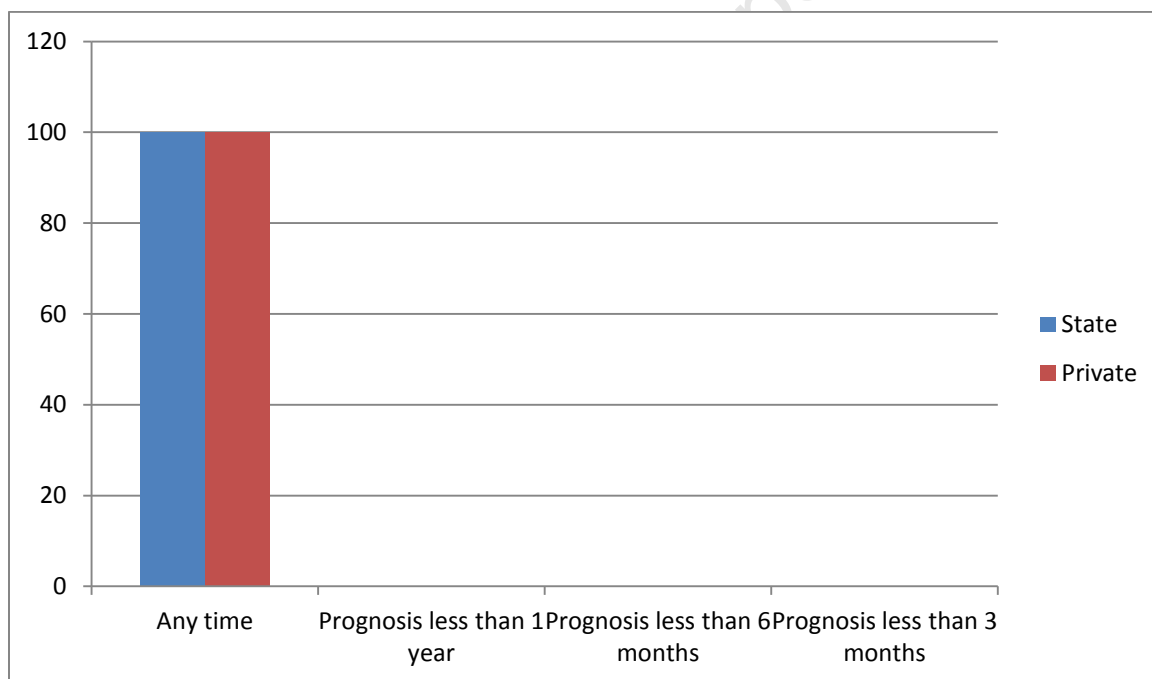


Figure 11: Morphine for pain control state vs. private

The meaning of hospice

One (3.2%) doctor said that referring a patient to hospice meant giving up on a patient. Twenty (62.5%) doctors said that referring a patient to hospice meant choosing professional supportive care ($p=0.146711$). One (3.2%) doctor said that referring a patient to hospice meant abandoning the patient. Twenty one (65.6%) doctors said that referring a patient to hospice meant that they work in partnership with a multidisciplinary palliative care team.

Meaning of hospice	State (n=14)	Private (n=18)
Giving up	0	1 (5.6%)
Supportive care	11 (78.6%)	9(50%) ($p=0.146711$)
Abandoning the patient	0	1 (5.6%)
Partnership with multidisciplinary team	9 (64.3%)	12 (66.7%)

Table 9: Meaning of hospice state vs. private

Only one doctor in private felt that referring to hospice means giving up and one private doctor said it meant abandoning the patient.

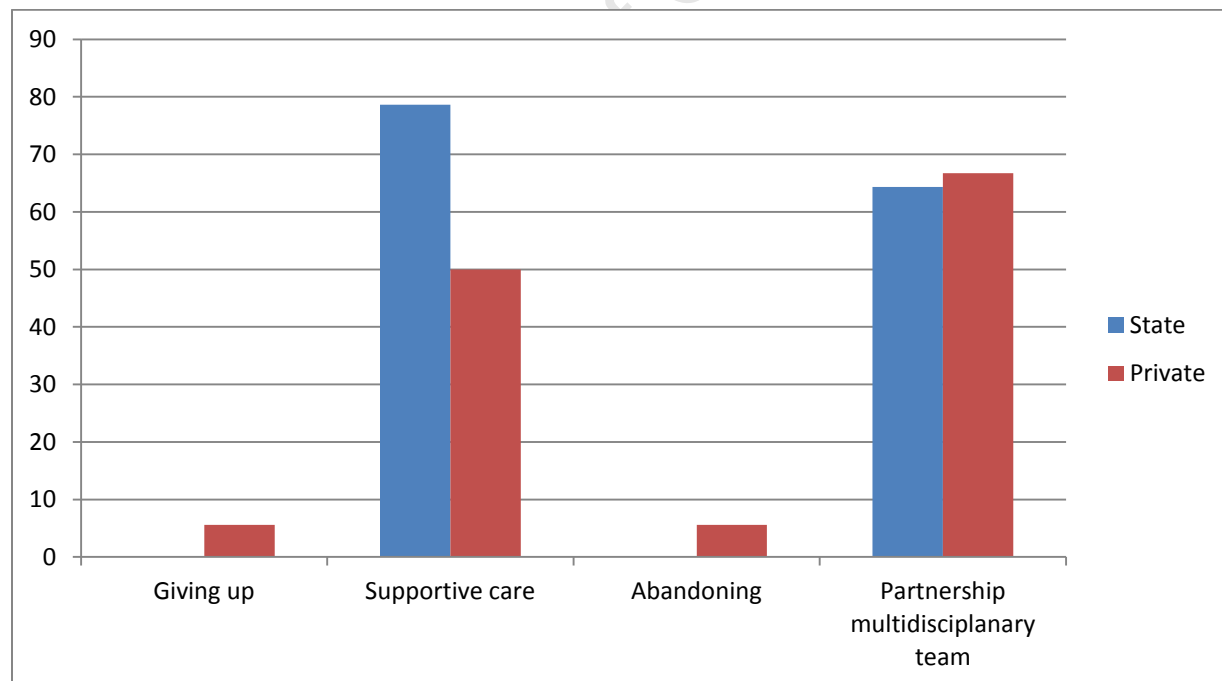


Figure 12: Meaning of hospice state vs. private

Training of oncologists

Only ten (31.3%) doctors in total felt they had good training in care of the dying ($p=0.001252$). Fourteen (43.8%) doctors felt they had good training in treating cancer. Nine (28.1%) doctors had good training in treating pain. Thirteen (40.6%) doctors said they felt their training as oncologists did not prepare them well for caring for dying patients as their training focused on cure only.

Training of oncologists	State (n=14)	Private (n=18)
Care for dying	0	10(55.6%) ($p=0.001252$)
Treating cancer	4 (28.6%)	10 (55.6%)
Treating pain	3 (21.4%)	6 (33.3%)
Training focused on cure	9 (64.3%)	4 (22.2%)($p=0.029262$)

Table 10: Training of oncologist's state vs. private

No state doctors felt that they received training in care for the dying which demonstrate a statistically significant difference with doctors working in private ($p=0.001252$). The majority of state doctors felt their training focused on cure, while the minority of private doctors agreed again demonstrating a significant difference ($p=0.029262$).

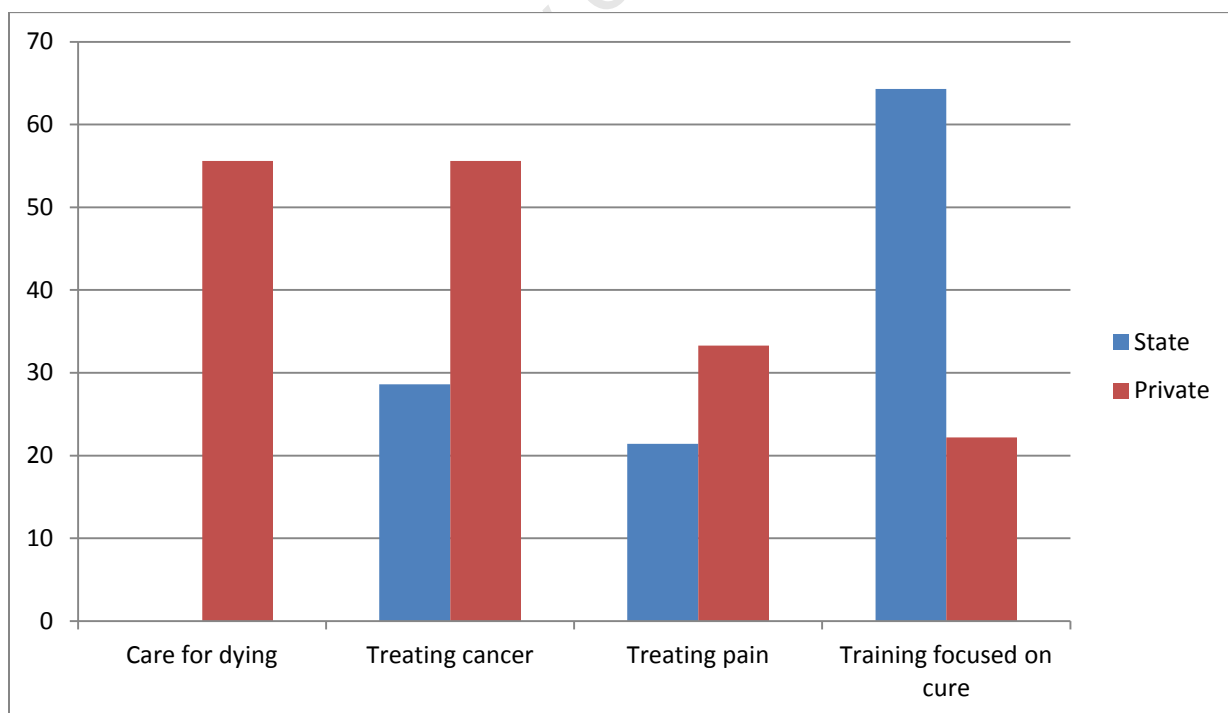


Figure 13: Training of oncologist's state vs. private

The role of the oncologist

Twenty seven (84.4%) doctors saw discussing and treating psychological problems arising due to cancer as part of their role as oncologist or medical officer in oncology($p=0.141963$). Fourteen (43.8%) doctors viewed discussing and treating spiritual issues the patient has as part of their role ($p=0.283121$). Seventeen (53.1%) doctors saw discussing and treating social problems the patient had as part of their role. Thirty (93.8%) doctors saw discussing and treating physical symptoms the patient had as part of their role.

Role of the oncologist	State (n=14)	Private (n=18)
Psychological problems	10 (71.4%)	17 (94.4%) ($p=0.141963$)
Spiritual issues	8 (57.1%)	6 (33.3%)($p=0.283121$)
Social problems	7 (50%)	10 (55.6%)
Physical problems	12 (85.7%)	18 (100%)
None of the above	0	0

Table 11: Role of the oncologist state vs. private

Fifteen percent of state doctors did not view treating physical problems as part of their role. Only half of the doctors agreed that social problems and spiritual issues form part of their role as oncologists.

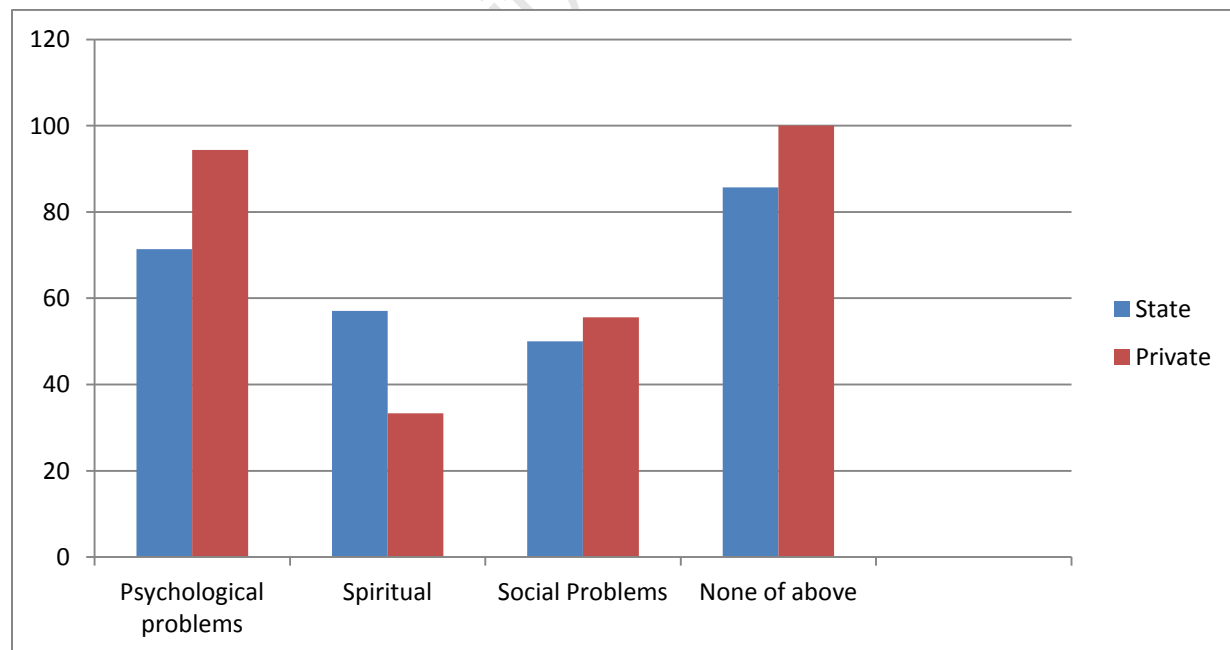


Figure 14: Role of the oncologist state vs. Private

Care in the terminal phase

Thirty two (100%) doctors were correctly of the opinion that a multi disciplinary palliative care team is the ideal combination of carers to care for a patient during the terminal stage. Two (6.3%) doctors said that an oncologist assisted by private home-nursing staff is the ideal combination of carers to care for the patient in the terminal phase. Two (6.3%) doctors said that an oncologist and hospital staff is the ideal combination of carers in the terminal phase. One (3.1%) doctor said that the oncologist and the oncology practice team is the ideal combination of carers in the terminal phase.

Care in the terminal phase	State (n=14)	Private (n=18)
Multidisciplinary team	14 (100%)	18 (100%)
Oncologist only	0	0
Oncologist + home nursing	0	2 (11.1%)
Oncologist + hospital staff	0	2 (11.1%)
Oncologist + practice team	0	1 (5.6%)

Table 12: Care in the terminal phase state vs. private

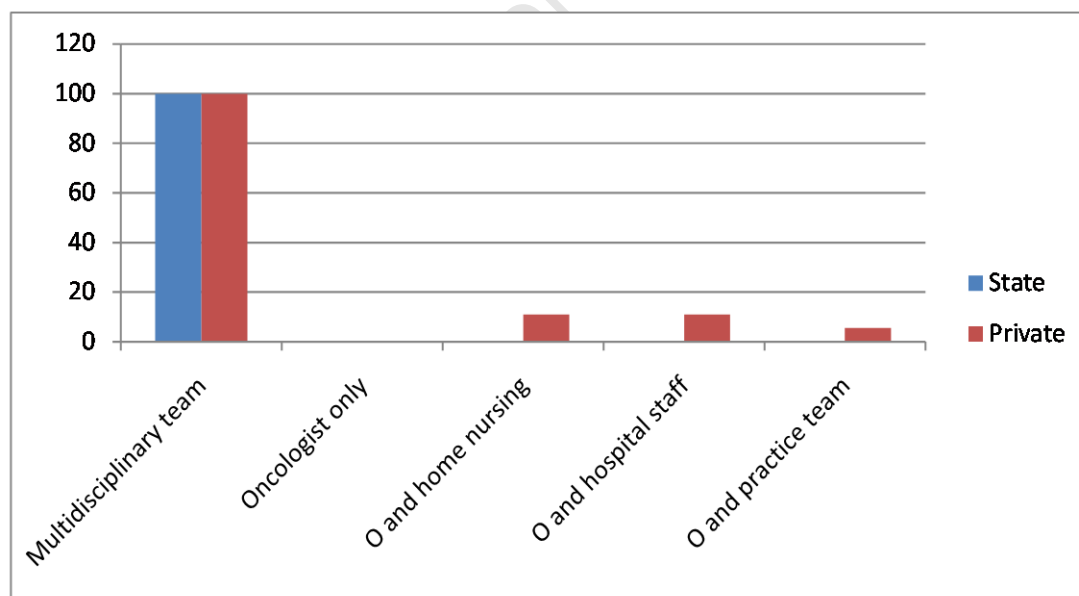


Figure 15: Providers of care in the terminal phase state vs. private

Explanation for increased dose of analgesics

Thirty two (100%) doctors correctly said the most likely explanation that a terminal cancer patient would request an increased dose of pain medication is that the patient is experiencing increased pain ($p=1.000$). Four (12.5%) doctors said the most likely reason for an increased dose of pain medication is a patient becoming depressed. Two (6.3%) doctors said the most likely explanation that a terminal cancer patient requests an increased dose of pain medication is that the patient is requesting more staff attention. It is important to note that none were concerned about addiction.

All the doctors felt that increased analgesic needs is due to increased pain.

Increased dose of analgesics	State (n=14)	Private (n=18)
Increased pain	14 (100%)	18 (100%) (p=1.000)
Addiction	0	0
Depression	2 (14.3%)	2 (11.1%)
Wanting staff attention	1 (7.1%)	1 (5.6%)

Table 13: Increased dose of analgesics state vs. private

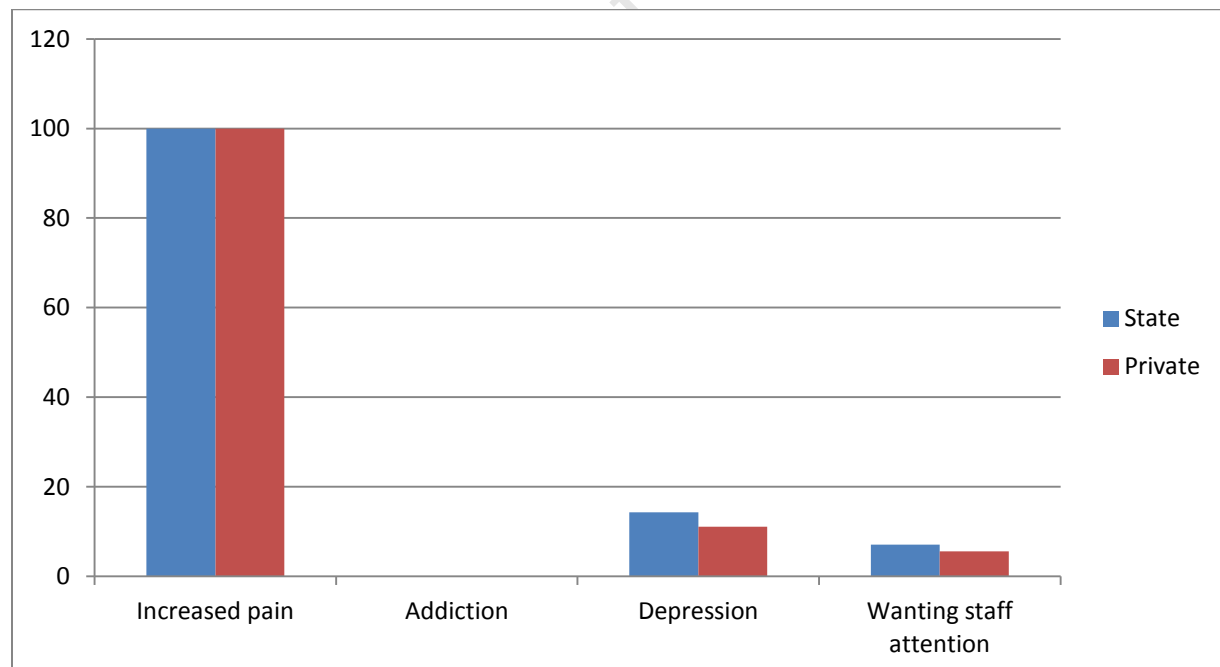


Figure 16: Reason for increased dose of analgesics needed state vs. private

BELIEF

Comfortable in treating pain

Fourteen (43.8%) doctors said they feel comfortable in treating their patient's pain all of the time ($p=0.283121$). Seventeen (53.1%) doctors said they feel comfortable in treating their patient's pain most of the time ($p=0.152669$). One (3.1%) doctor sometimes felt comfortable in treating his/her patient's pain.

Comfortable in treating pain	State (n=14)	Private (n=18)
All the time	8 (57.1%)	6 (33.3%) ($p=0.283121$)
Most of the time	5 (35.7%)	12 (66.6%) ($p=0.152669$)
Sometimes	1 (7.1%)	0
No, never	0	0

Table 14: Comfortable in treating pain state vs. private

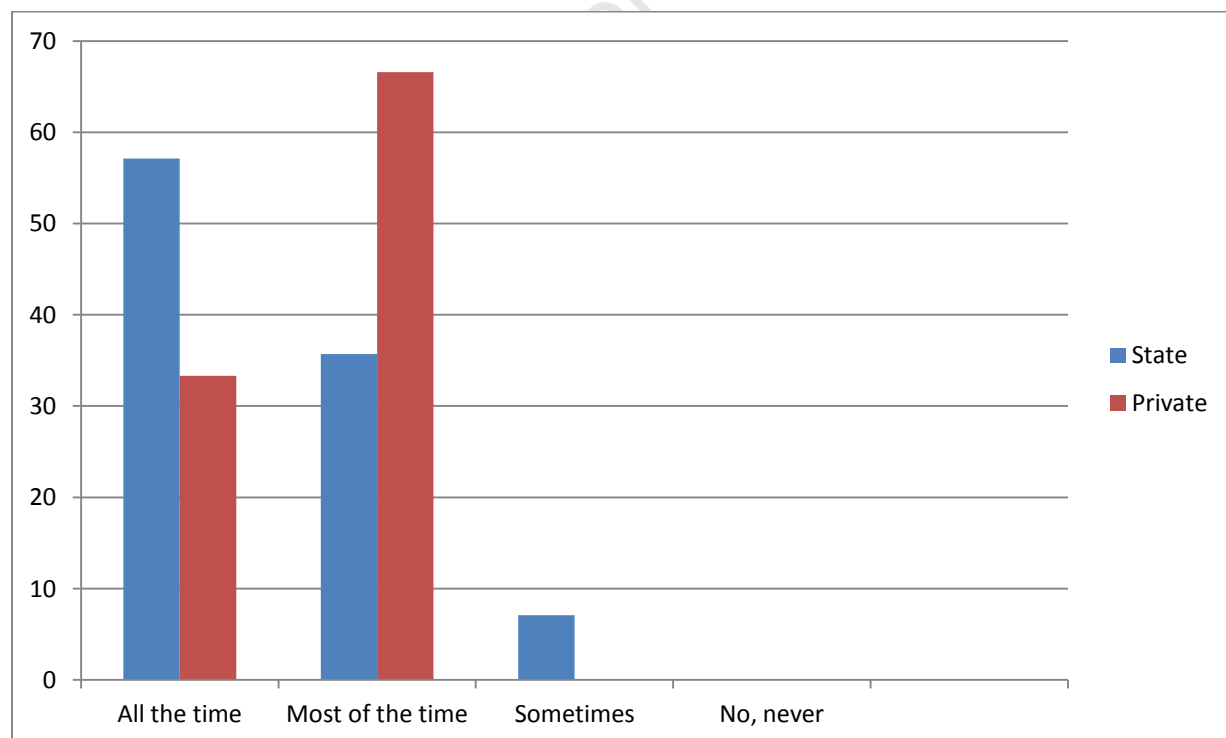


Figure 17: Oncologists comfortable in treating pain state vs. private

Feelings when cure is no longer an option

One (3.2%) doctor felt that he/she failed the patient when a patient reached the point when cure is no longer an option. Thirty (96.8%) doctors felt they did their best in providing the best possible treatment when a patient reached the point where cure is no longer an option ($p=0.437500$). One doctor wrote none of the above. One marked both failed the patient and did my best.

Feelings	State (n=14)	Private (n=18)
I failed the patient	1 (7.7%)	0
I failed the family	0	0
I failed myself	0	0
I did my best	13 (92.3%)	18 (100%) ($p=0.437500$)
None of the above	1 (7.7%)	0

Table 15: Feelings of doctors when cure is no longer an option state vs. private

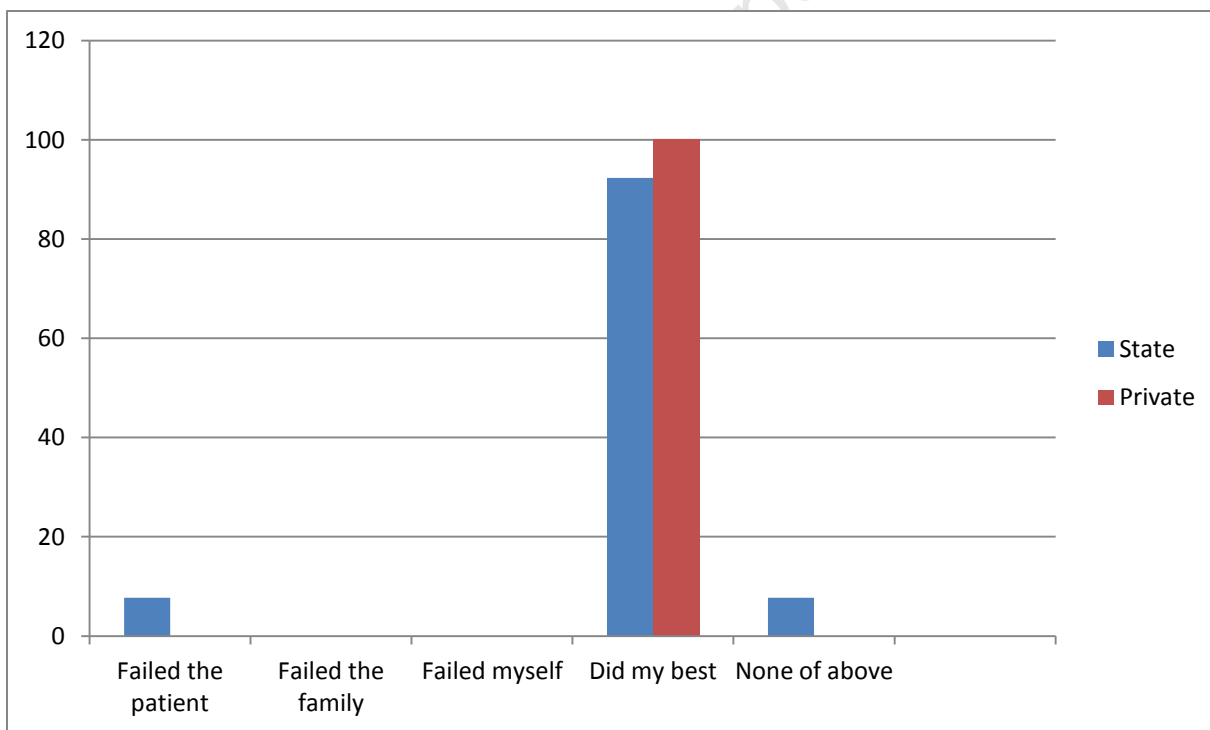


Figure 18: Oncologist's feelings when cure is no longer an option state vs. private

Reason for non- referral

Five doctors (15.6%) were of the opinion that the most likely reason for not referring of patients to hospice was that referral to hospice meant loss of hope for the patient. Four doctors (12.5%) said that doctor's previous dissatisfaction with service rendered by hospice was the most likely reason for not referring patients to hospice. Sixteen doctors (50%) stated that hospice is not available in their area or not accessible for the patients ($p=0.000965$). Twenty four doctors (75%) said the most likely reason for non-referral of patients to hospice is that the patient was being resistant to referral to hospice ($p=0.251672$). One doctor (3.1%) said he/she, as a doctor, did not want to lose control of the treatment of the patient. One doctor (3.1%) stated that the most likely reason for non-referral was because medical aid does not provide benefits for palliative care or hospice care. Fourteen doctors (43.8%) said that the patient's family refused referral to hospice.

Reason for non- referral	State (n=14)	Private (n=18)
Means loss of hope	1 (7.1%)	4 (22.3%)
Previous dissatisfaction	0	4 (22.3%)
Not accessible for patient	12 (85.7%)	4 (22.3%) ($p=0.000965$)
Patient resistance	9 (64.3%)	15 (83.3%)($p=0.251672$)
Don't want to lose control	0	1 (5.6%)
No medical aid benefits	0	1 (5.6%)
Family refuse referral	5 (35.7%)	9 (50%)

Table 16: Reason for non-referral to hospice state vs. private

It is interesting to note that the majority of the state doctors remarked that hospice is not accessible to their patients. Patients are referred from the whole of the Western Cape to both state and private facilities.

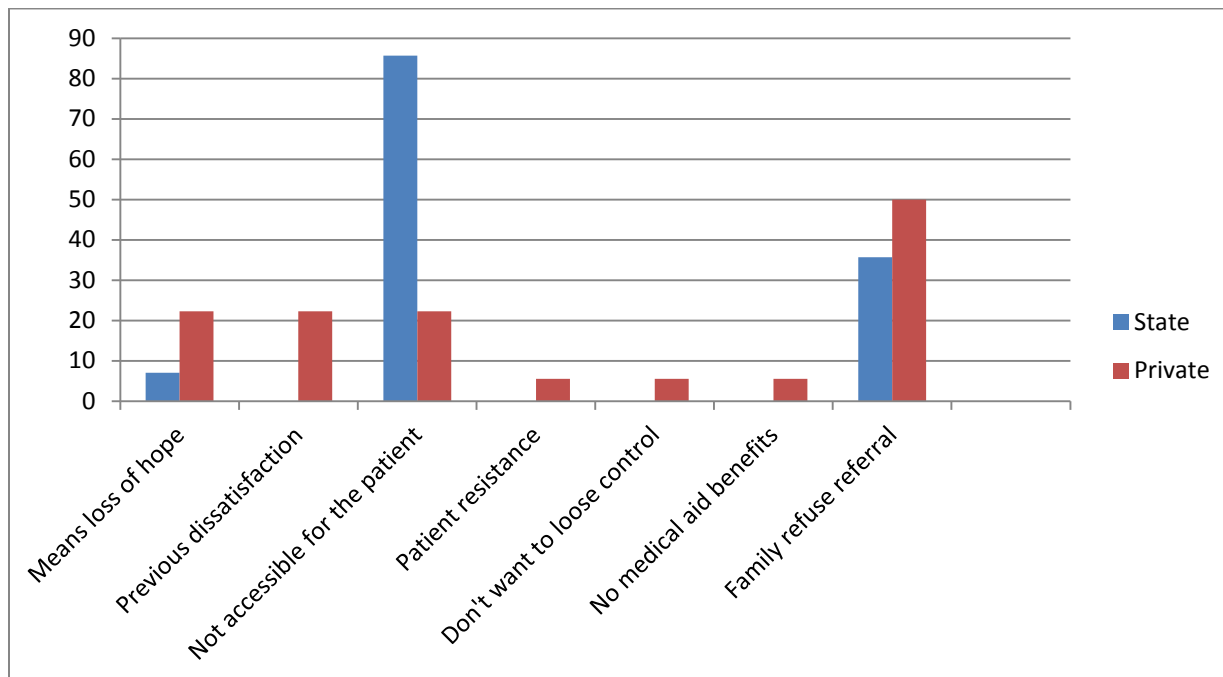


Figure 19: Reason for non- referral to hospice state vs. private

Reason for patient resistance to hospice seven doctors (21.9%) said the main reason for patient resistance to referral to hospice is fear of the unknown. Thirty one doctors (96.9%) stated that they thought the main reason for patient resistance to referral to hospice is the perception of the patient that hospice means the end of life ($p=0.437500$). Three doctors (9.4%) said they thought the main reason for resistance to referral to hospice is the perception of the doctor that he/she is giving up on his/her patient. Five doctors (15.6%) said the main reason for a patient's resistance to referral to hospice is bad memories from the patient's perspective if the patient had lost a family member ($p=0.354700$). Two doctors (6.3%) said the main reason for patient resistance to referral to hospice is because medical aids do not provide benefits for palliative or hospice care.

Patient resistance	State (n=14)	Private (n=18)
Fear of unknown	4 (28.6%)	3 (16.7%)
Patient perception	13 (92.9%)	18 (100%). ($p=0.437500$)
Doctor perception	0	3 (16.7%)
Patient bad memories	1 (7.1%)	4 (22.3%) ($p=0.354700$)
No medical aid benefits	1 (7.1%)	1 (5.6%)

Table 17: Reasons for patient resistance state vs. private

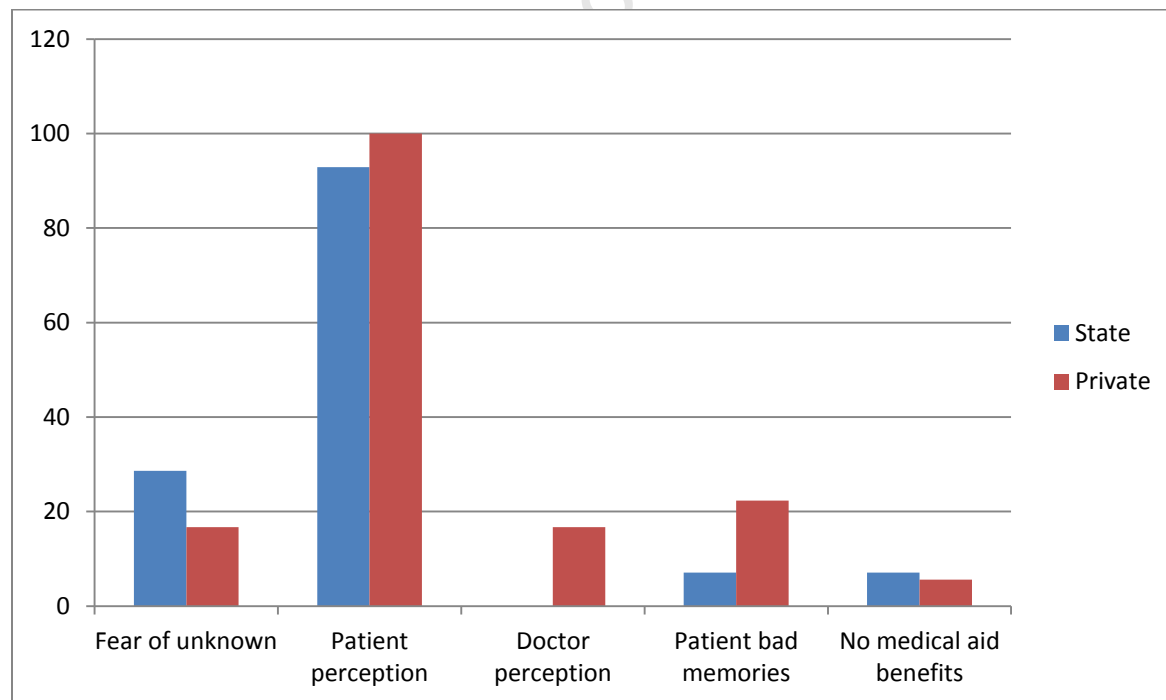


Figure 20: Patient resistance to hospice referral state vs. private

Place of death

Three (9.4%) doctors believe the doctor should decide where a patient would like to die. Thirty one (96.9%) doctors believe the patient should decide where he/she would like to die ($p=1.00000$). Fifteen (46.9%) doctors said they believe the family should decide where the patient should die. Six (18.8%) doctors believe the primary caregiver should decide where the patient dies.

Place of death	State (n=14)	Private (n=18)
Doctor	2 (14.3%)	1 (5.6%)
Patient	14 (100%)	17 (94.4%) ($p=1.00000$)
Family	6 (42.9%)	9 (50%)
Primary care giver	2 (14.3%)	4 (22.2%)

Table 18: Place of death state vs. private

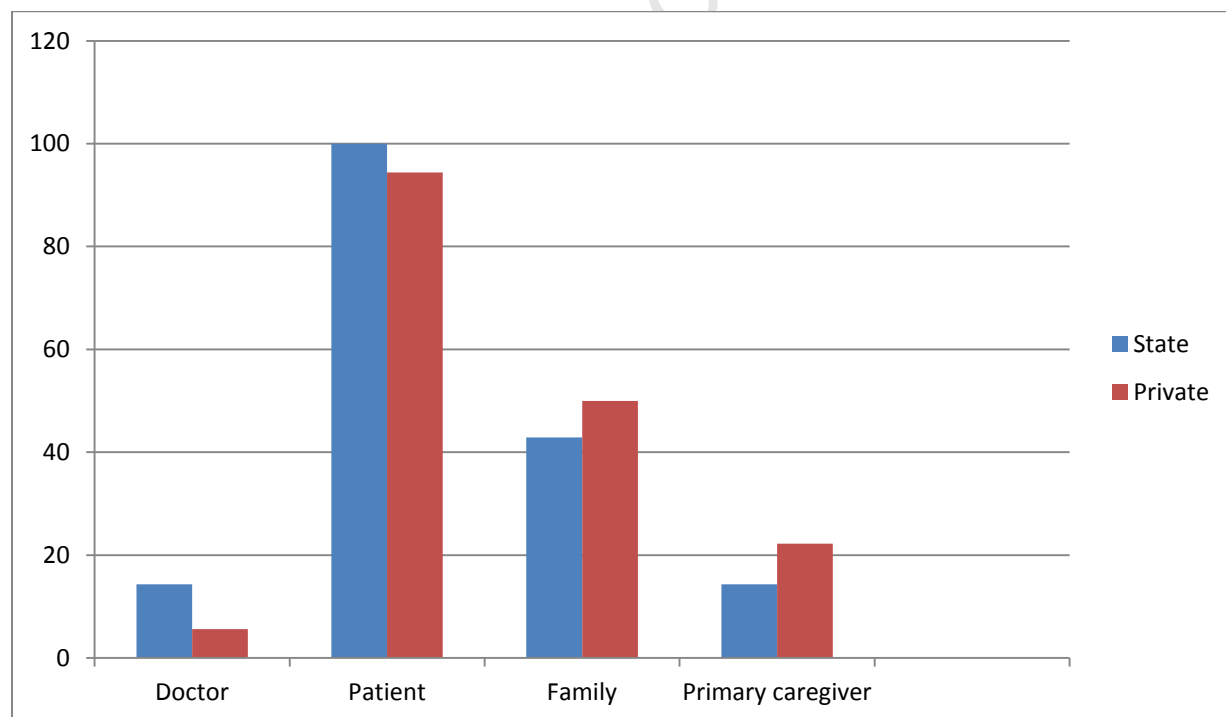


Figure 21: Place of death state vs. private

PRACTICE

Use of WHO guidelines for pain control

Seventeen (53.1%) doctors said they always use the WHO stepladder guidelines regularly when prescribing analgesics for cancer pain ($p=1.000000$). Eleven (34.4%) doctors stated they sometimes use the WHO stepladder guidelines. Two (6.3%) doctors use the WHO stepladder guidelines only in patients with difficult pain.

Use of WHO guidelines	State (n=14)	Private (n=18)
Yes, always	7 (58.3%)	10 (55.6%) ($p=1.000000$)
No, never	0	0
Sometimes	5 (41.7%)	6 (33.3%)
Only for difficult pain	0	2 (11.1%)

Table 19: Use of WHO guidelines state vs. private

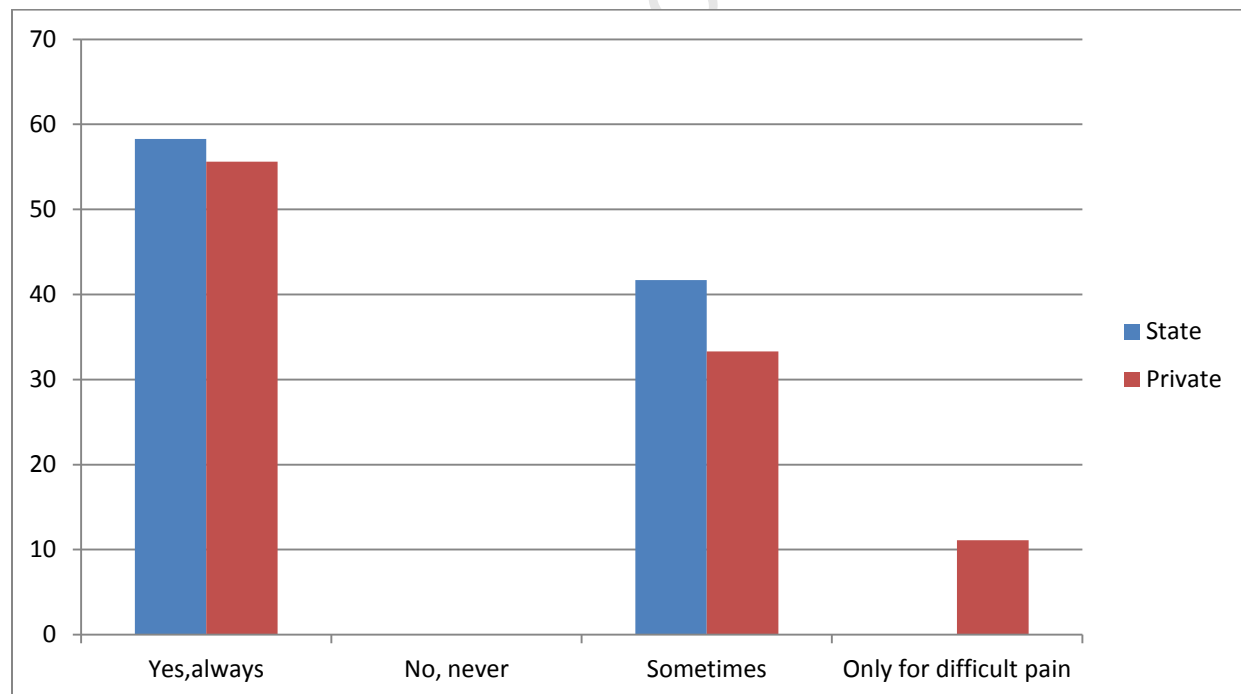


Figure 22: Use of WHO guidelines for pain control state vs. private

Ease of communication about disease progression

Twenty three (71.9%) doctors said they find it easy to communicate information about disease progression and they give full information to the patient ($p=1.00000$). Fourteen (43.8%) doctors said they find it easy to communicate information about disease progression and they discover what the patient wants to know and share the relevant information with him/her. Two (6.3%) doctors said telling the patient the disease is not curable takes away the patient's hope.

Ease of communication about disease progression	State (n=14)	Private (n=18)
Full information to patient	10 (71.4%)	13(72.2%)($p=1.000000$)
What the patient wants to know	8 (57.1%)	6 (33.3%)
Full information to family	0	0
Takes away patient's hope	2 (14.3%)	0

Table 20: Ease of communication about disease progression state vs. private

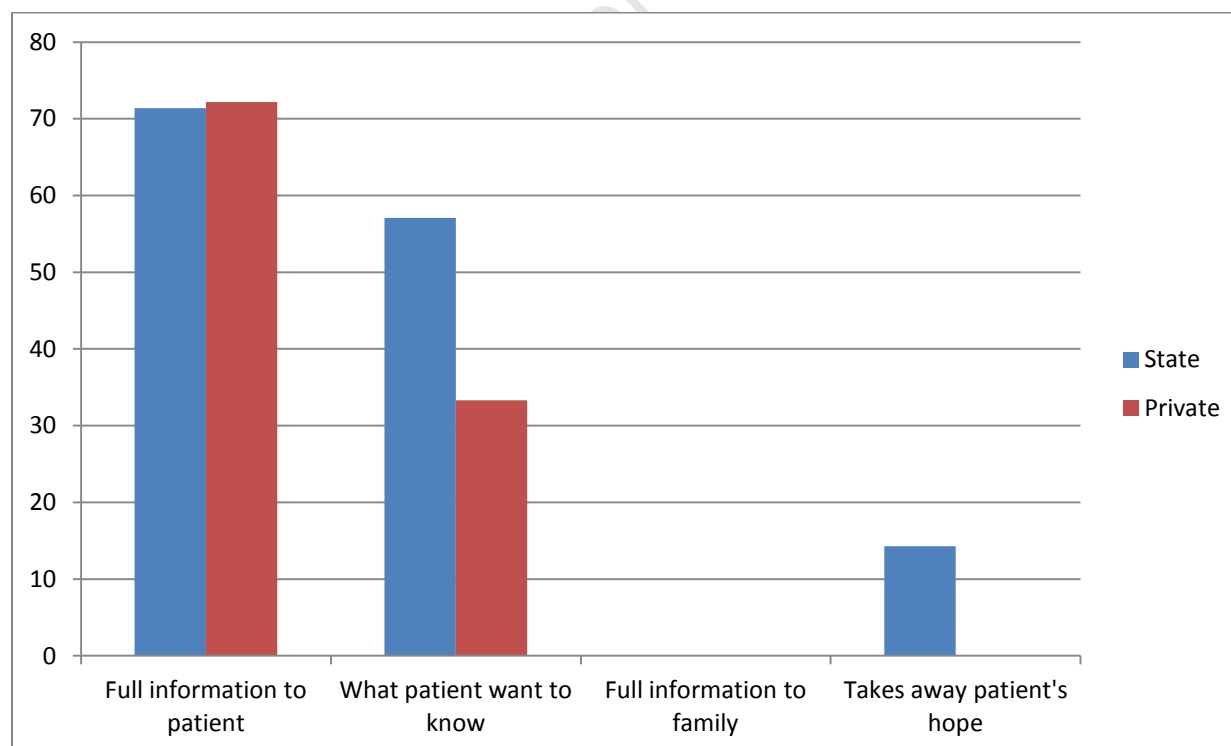


Figure 23: Ease of communication about disease progression state vs. private

Discussing end of life issues when cure is no longer an option

Thirty (93.8%) doctors stated that they feel comfortable in discussing death and dying with their patients when cure is no longer the aim of treatment ($p=0.183468$). Five (15.6%) doctors said they refer the patient to a private counselor. Ten (31.3%) doctors said they refer the patient to hospice when cure is no longer the aim of treatment.

Comfortable discussing end-of-life issues	State (n=14)	Private (n=18)
Yes, discuss death and dying	12 (85.7%)	18(100%) ($p=0.183468$)
Refer to private counselor	1 (7.1%)	4 (22.2%)
Refer to hospice	5 (35.7%)	5 (27.8%)
Tell family but not patient	0	0

Table 21: Comfortable discussing end-of-life issues state vs. private

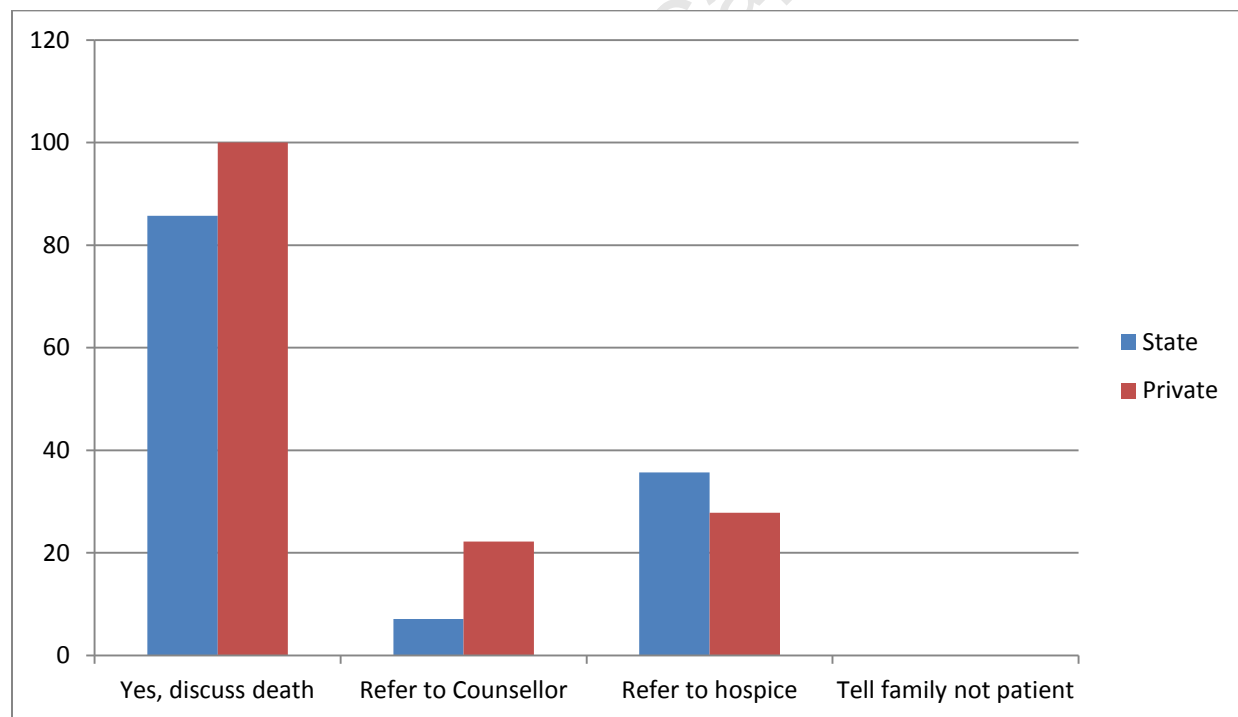


Figure 24: Oncologist comfortable in discussing end-of-life issues state vs. private

Treatment of patients when cure is no longer an option

Twelve (37.5%) doctors send the patient back to the GP or primary clinic when cure is no longer the aim of treatment ($p=0.009998$). Twenty six (81.3%) doctors refer the patient to hospice when cure is no longer the aim of treatment ($p=0.023800$). Twenty eight (87.5%) doctors continue to treat the patient to the best of my ability. Eleven (34.4%) doctors refer their patients to a palliative care team.

Further treatment	State (n=14)	Private (n=18)
Refer patient to GP or primary clinic	9 (64.3%)	3 (16.7%) ($p=0.009998$)
Refer to hospice	14 (100%)	12 (66.7%) ($p=0.023800$)
Continue to treat	11 (78.4%)	17 (94.4%)
Refer to PC team	4 (28.6%)	7 (38.9%)

Table 22: Further treatment state vs. private

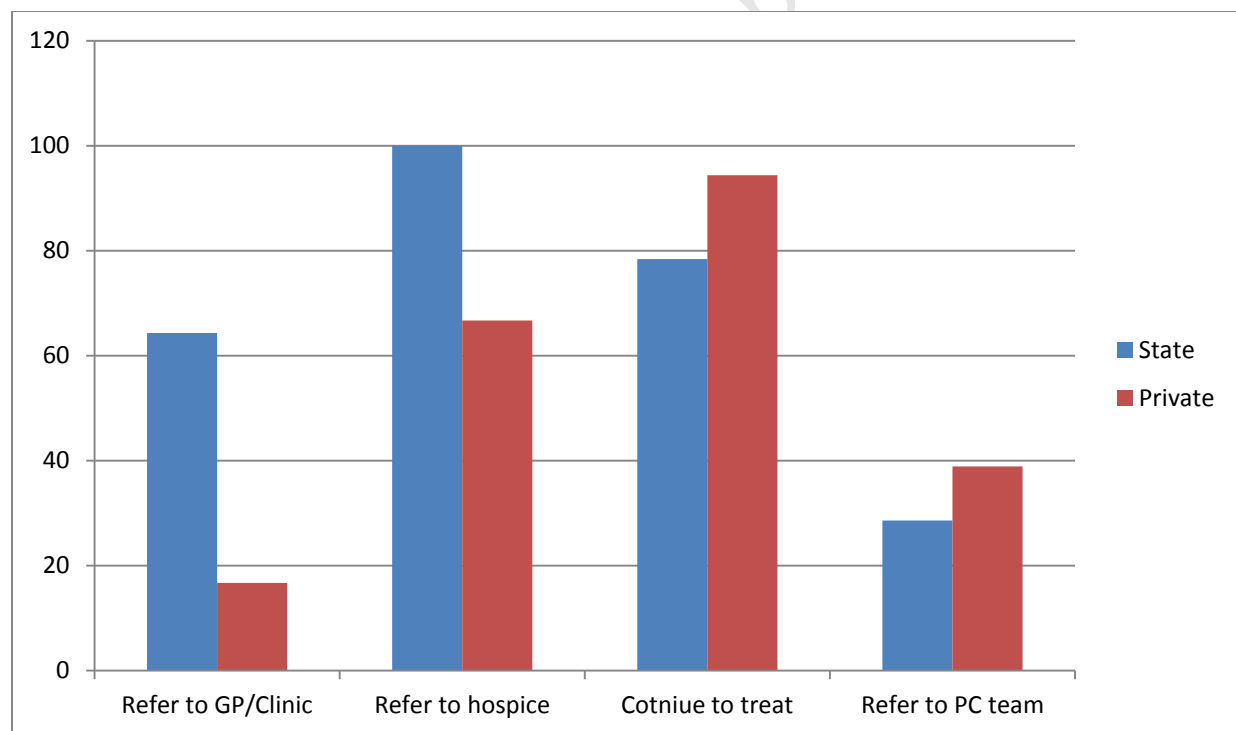


Figure 25: Further treatment state vs. private

Referral to hospice

Sixteen (50%) doctors always refer their patients with progressive incurable disease to hospice as it gives the patient and family additional care ($p=0.285163$). Nineteen (59.4%) doctors refer patients with progressive incurable disease to hospice if it is the patient's choice ($p=0.149183$).

Referral to hospice	State (n=14)	Private (n=18)
Yes, always	9 (64.3%)	7 (38.8%) ($p=0.285163$)
Yes, if patient's choice	6 (42.8%)	13 (72.2%) ($p=0.149183$)
Never, oncology team manage patient	0	0
Sometimes if funds depleted	0	0

Table 23: Referral to hospice state vs. private

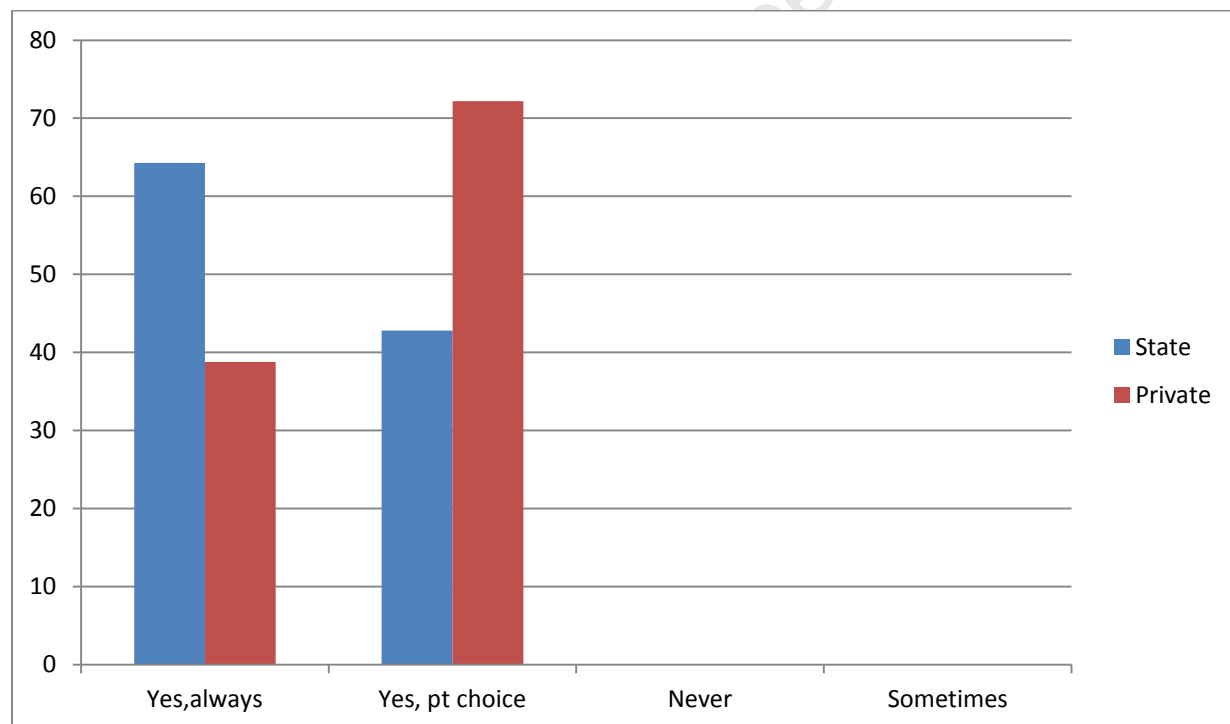


Figure 26: Referral to hospice state vs. private

Referral to other disciplines

Thirty one (96.9%) doctors refer their patients to a social worker. Eighteen (56.3%) doctors refer their patients to a spiritual counsel or/religious worker ($p=0.489590$). Nineteen (59.4%) doctors refer their patients to a psychologist. Twenty two (68.8%) doctors refer their patients to a support group.

Referral to other disciplines	State (n=14)	Private (n=18)
Social worker	13 (92.9%)	18 (100%)
Spiritual counselor	9 (64.3%)	9 (50%) ($p=0.489590$)
Psychologist	7 (50%)	12 (66.7%)
Support group	8 (57.1%)	14 (77.8%)

Table 24: Referral to other disciplines state vs. private

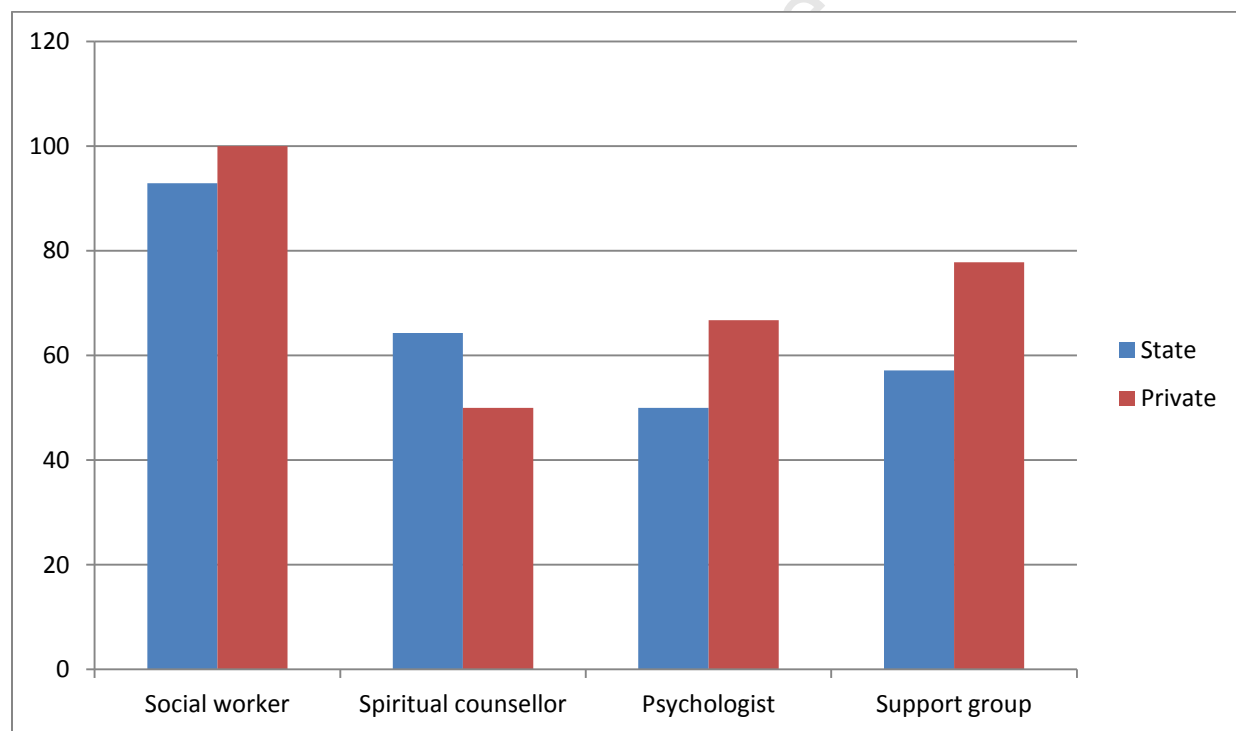


Figure 27: Referral to other disciplines state vs. private

Discussion about place of death

Twenty seven (84.4%) doctors will discuss the place of death with the patient ($p=0.141963$). Twenty four (75%) doctors will discuss the place of death with the family ($p=0.096359$). Fifteen (46.9%) doctors will discuss the place of death with the primary caregiver. Two (6.3%) doctors never discuss the place of death with the patient, the family or primary caregiver.

Discussion about place of death	State (n=14)	Private (n=18)
Patient	10 (71.4%)	17 (94.4%)($p=0.141963$)
Family	8 (57.1%)	16 (88.9%)($p=0.096359$)
Primary caregiver	6 (42.9%)	9 (50%)
It is never discussed	2 (14.3%)	0

Table 25: Discussion about place of death state vs. private

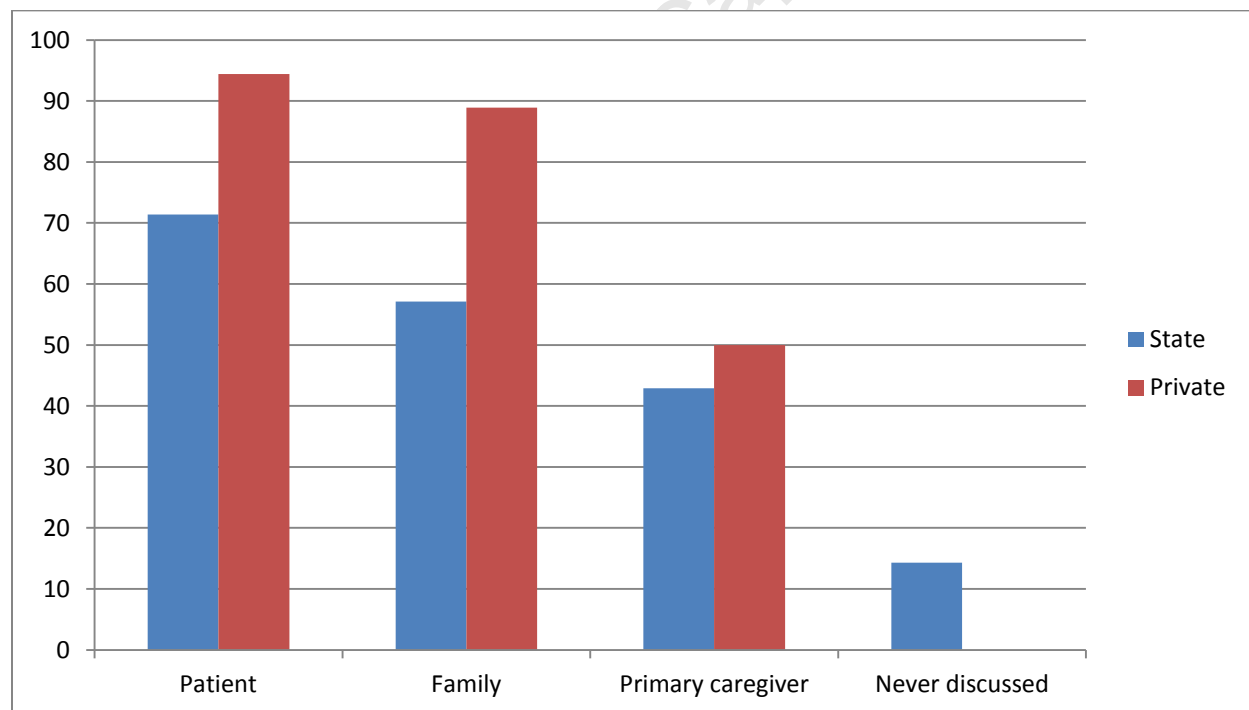


Figure 28: Discussion about place of death state vs. private

Timing of referral to hospice

Twenty (62.5%) doctors said they will refer terminally ill patients to hospice ($p=1.0000$). Nine (28.1%) doctors said they will refer dying patients to hospice. ($p=0.001805$) Twenty seven (84.4%) doctors will refer patients with end stage disease to hospice. Nineteen (59.4%) doctors will refer patients with disease progression to hospice.

Timing of referral to hospice	State (n=14)	Private (n=18)
Terminal ill	9 (64.3%)	11(61.1%) ($p=1.00000$)
Dying patient	0	9 (50%) ($p=0.001805$)
End stage disease	11 (78.6%)	16 (88.9%) ($p=0.0631257$)
Disease progression	8 (57.1%)	11 (61.1%)

Table 26: Timing of referral to hospice state vs. private

Referral takes place late and it is concerning that 50% of private oncologists refer dying patients to hospice.

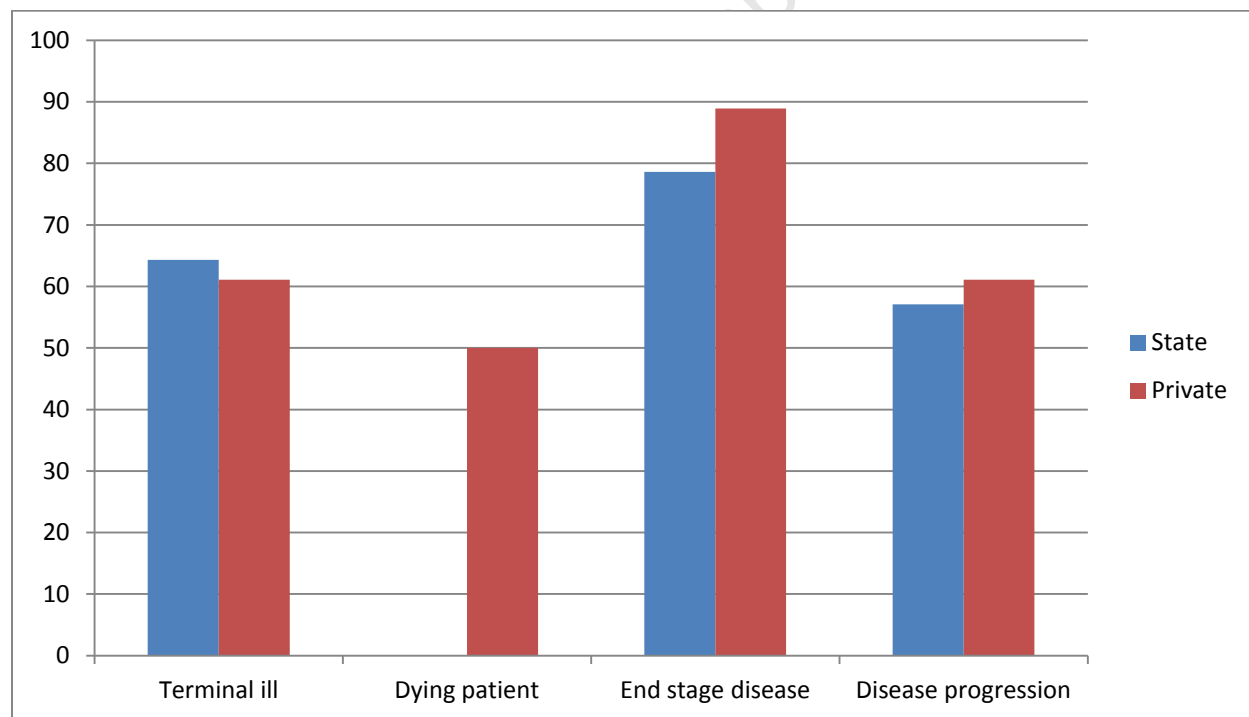


Figure 29: Timing of referral to hospice state vs. private

From the results it is clear there were statistical significant differences in a number of questions. This will be discussed in chapter 6.

Chapter 6

DISCUSSION

Research on Palliative care in South Africa is limited. To the researcher's knowledge, this is the first study on referral of patients to hospice by oncologists done in South Africa.

The concept of this dissertation arose from the perception of the researcher, after years in general practice and working as a volunteer doctor at a hospice, that hospice referral of patients come too late in the disease progression for the patient really to experience the benefits that palliative care and hospice have to offer.

In this chapter the results of the study will be discussed under the headings knowledge, attitudes, beliefs and practice and the responses of doctors working in oncology in the state hospital will be compared to the responses of the oncologists in private practice. The term state doctors and private doctors will be used.

Although the response rate was 94%, one of the limitations of this study was that there were only 32 questionnaires due to the limited number of doctors working in oncology in the Western Cape.

A small study can deliver statistically significant results, despite the small number of subjects. The statistical tests applied can differ and show statistical significance or otherwise. These results cannot necessarily be generalised to the whole of South Africa, but they provide valuable information and a foundation for further research on oncology practice.

Reviewing responses on questions about practice will assess reports of behaviour and not behaviour itself and can be influenced by social desirability and lack of recall of detail of behaviour.⁵¹ This opinion may also be true for questions on attitude and belief.

The results for doctors in the academic state facility will be discussed and compared with those for oncologists in private practice. It is important to keep in mind that the responders could mark more than one answer per question. This decision may be viewed as a limitation but it enabled the researcher to gain more in depth information from the respondents.

DEMOGRAPHIC ANALYSIS OF PARTICIPANTS

There were no differences between the views of male and female doctors. The average age of doctors in the state facility was 36.2 years and for those in private practice 47.4 years. It was shown by the results that more experienced doctor's work in private practice. The oncologists in training usually start specialising soon after graduation from medical school and will contribute to the younger median age of state doctors.

KNOWLEDGE

Pain may be the presenting symptom in cancer like bone, colorectal, lung, pancreatic and other. Miser reported that 62% of children experienced pain as an initial symptom of cancer.¹³⁰ Pain may be expected by cancer patients as part of their disease and is therefore often underreported. Impeccable assessment of pain in the individual patient and optimal treatment is crucial in preserving quality of life.

According to the results, the majority of doctors working in oncology are following the WHO guidelines for pain control.¹³¹ Besides the use of the analgesic ladder it should also imply using the recommendations for the correct use of analgesics, namely oral analgesics to be given at regular intervals. The analgesics should be prescribed according to the pain intensity experienced by the patient.

Dosing should be individualised and a written personal program for the patient may be enhancing compliance and be helpful in obtaining optimal pain control.¹²⁹ Only one oncologist in private reported using only morphine to initiate pain control while a third of the respondents chose “all of the above” meaning they are using paracetamol, NSAIDs and morphine to initiate pain control.

This may be due to multiple factors, including the fact that pain treatment should be initiated at an appropriate level for the degree of pain which may be mild, moderate or severe and the medication used for initiating treatment should correspond.

All the state doctors and the majority of private doctors (83%) correctly said that pain in a cancer patient can be caused by the tumour, complications of cancer, anticancer treatment and unrelated conditions (all of the above). This is in keeping with what was expected and what was found in the literature and it can be assumed that this understanding contributes to good assessment of patients' pain. The majority of state doctors (71.4%) and 100% of private doctors knew that NSAIDs, corticosteroids and tricyclic antidepressants are all useful analgesic adjuvants. The results for the state doctors were less than expected for doctors working in an academic setting.

The majority of doctors who took part in this survey had good knowledge of cancer pain and the treatment thereof using the WHO analgesic ladder. This survey in itself may have prompted doctors to be more alert about pain control. If this survey is viewed as objective and accurate, pain management is good and consistent with the literature reviewed.

A future survey on analgesic therapy for cancer patients and the use of the adapted analgesic ladder may identify the need for further education in pain control.

The majority of doctors (both hospital and private) indicated correctly that private nursing care in the patients' home offers assistance with activities of daily living (78.1%), care focused on preserving quality of life (62.5%) and physical care (56.3%). Only a third of both groups (31.3%) felt that private nursing care gave good symptom control.

This is less than expected and can be due to lack of communication between the private nurse practitioners and the treating doctor regarding symptom control. Less than a third of doctors, in fact 35.7% of the state doctors and 22.4% of the private doctors said that spiritual care was provided by private nursing care.

The majority of the participating doctors knew that hospice service offers physical, psychosocial and spiritual care. All the state doctors said that hospice service includes treatment focused on preserving quality of life during disease progression and deterioration of the condition. All the private doctors knew that hospice offers psychosocial support and 90% of all doctors said that hospice managed distressing symptoms. Only 57% of state doctors stated that hospice offer spiritual care while nearly 90% of private doctors were aware of this service. It is encouraging that the majority of doctors are familiar with all of the services that hospice offers. However, more emphasis should be placed on promoting spiritual care to be part of holistic care of patients. Holistic care in the palliative setting includes physical, psychosocial as well as spiritual care of the patient. Spiritual needs should be explored and if the treating doctor is uncomfortable in dealing with or meeting the spiritual needs of the patient, the patient should be referred to a counselor.

There is a big difference in the services offered by private nursing care and palliative care. Hospice nursing staff is trained in palliative care whereas few private nursing staff have training in palliative care. More needs to be done to bring this to the attention of doctors and patients. Private home nursing can be ordered while hospice is treating the patient as these two services are complementary to each other. However it seems that the understanding is that a patient should be referred to either one or the other.

Nearly 90% of private doctors understood palliative care to include pain and symptom control, holistic approach and psychosocial support. Nearly two thirds of hospital doctors understood palliative care to be pain and symptom control and a support system to assist the patient to live as actively as possible. Only 42.9% of state doctors and 88.9% of private doctors understood palliative care to be psychosocial support.

Only a third of doctors, both hospital and private, viewed palliative chemotherapy as palliative care.

In general the private doctors displayed a better understanding of the philosophy of palliative care than the state doctors.

This finding is in keeping with the findings of the literature review that demonstrated a need for training of all specialties in the principles of palliative care.⁴³ The younger doctors did not have superior knowledge regarding palliative care as expected when compared with older doctors. The results regarding knowledge of hospice services and the understanding of palliative care raise the question of how this translates into hospice referrals.

ATTITUDES

All doctors who took part both in hospital and private practice, will prescribe morphine as analgesic for severe pain at any stage of the patient's disease. This illustrates there is broad knowledge that pain should be treated according to the needs of the patient and not the needs of the disease. Morphine is a very effective, relatively inexpensive analgesic that is successfully used worldwide and should not be reserved for terminal patients. New opioids such as tramadol have been added to the adapted analgesic ladder. Opioids can also be used to treat non-cancer pain.¹²⁹ As reported both state and private doctors are confident in prescribing morphine for cancer pain. This result is contrary to the findings of Finlay I and Fakroodeen.^{60,123} This observation may be due to the fact that there may have been more training in pain management since these studies were conducted.

The reported competence in pain management may influence referral to hospice. The doctor might be under the impression that if the patient's pain is under control hospice referral is not indicated. It is important to remind doctors that hospice provides holistic care and offers physical psychosocial and spiritual care to the patient and not only pain management.

All state and private doctors said the most likely explanation that a terminal cancer patient would request an increased dose of pain medication, is that the patient is experiencing increased pain. No doctors said that the request is due to addiction and it is encouraging that doctors recognize that addiction is not a problem in prescribing analgesics for cancer pain.

However, this view may be because doctors consider that “what does it matter at this stage”, rather than a real recognition that addiction rarely occurs.¹³² Patients and families are often concerned about the possibility of addiction and reassurance and education is indicated. Caution is necessary in patients who have previously been addicted to street drugs.

Depression was mentioned as a possible reason for requesting increased pain medication by two doctors in both state and private. Depression in cancer patients can at times be overlooked and symptoms are often underreported by patients as they expect to have a depressed mood at times. One doctor in both state and private mentioned that requesting more staff attention can be a reason for requesting an increased dose of pain medication. If a patient is demanding more staff attention there often is another underlying problem that needs to be explored and addressed like psychological, spiritual or social issues. Sufficient time should be spent during consultation to assess the patient’s psychological, spiritual and social circumstances and address the needs that are identified. Regular reassessment should take place.

No state doctors felt that referring a patient to hospice meant giving up on a patient or abandoning a patient. One doctor in private felt referring a patient to hospice means giving up on a patient and one felt it meant abandoning the patient. However, three quarters of state doctors and half of the private doctors felt that referring the patient to hospice meant supportive care, while two thirds of all doctors felt it meant working in partnership with a multidisciplinary team.

Although the majority of doctors understood that hospice offers supportive care by a multidisciplinary team, it should be explored why some private doctors felt hospice means abandoning and giving up on a patient. This may be due to misconceptions of services offered by hospice or previous experiences of marginalisation by hospice in the past. Effective communication between hospice and the referring doctor may be able to address this misconception.

It should be emphasized that hospice is not a place, but rather a philosophy of care. This care can be delivered in a number of settings of which the patient's home will be the place of choice for the majority of patients.

As expected, all state doctors and private doctors were of the opinion that a multidisciplinary palliative care team is the ideal combination of carers to care for a patient during the terminal phase. No doctors felt that the oncologist should be caring for the patient on his/her own. However, in practice we find that not all terminally ill patients are referred to palliative care services. This may be due to a number of factors including that palliative care services are not available and accessible to all patients especially in the rural areas. According to HPCA there are at present 196 hospices of which 26 are fully accredited in South Africa with regard to HPCA Standards of governance, management and palliative care. These hospices care for approximately 72000 patients per year. The estimated number of patients that are in need of palliative care in South Africa is +/- 450 000 patients.¹¹⁹ Accreditation is a long administrative process and not all hospices may be able to comply with regulation. The 170 partially HPCA accredited or non-accredited hospices offer valuable service to patients and family members. The training offered by the hospice organisations improves the quality of palliative care available to patients.

The development of palliative care centres throughout the country will be ideal, but financial constraints might hamper this process. By training of all clinic and hospital staff in the principles and practice of palliative care existing resources can be utilised to benefit patients and their families.

Although the results confirmed understanding of the need for a multidisciplinary palliative care team, further investigation regarding actual referral patterns will give more clarity regarding facilities.

The majority of state doctors (64.3%) felt that their oncology training focused on cure while 22.2% of private doctors felt their training focused on cure only($p=0.029262$).

This may be a factor which leads to a higher referral rate to hospice from state hospitals. It was interesting to note that less than a third of all doctors felt they had good training in pain control.

Not one of the state doctors felt they had good training in care of the dying while more than half of private doctors (55.6%) felt they had good training in care of the dying ($p=0.0001252$). This is concerning as the state doctors are representing the younger doctors and again highlights the need for incorporating palliative care into the undergraduate and postgraduate curricula of all doctors.⁴³ It also emphasizes the view that modern medicine still sees death as the ultimate failure.

This is an opportunity for further education and training that may be done in collaboration with hospices.

The majority of doctors viewed discussing and treating physical symptoms as part of their role. However, it is concerning that 15% of state doctors did not view discussing and treating physical symptoms as part of their role. The reason for this response is not clear. Treating psychological problems arising from cancer was viewed by 94.4% of private doctors and 71% of state doctors as part of their role. Half of the state doctors viewed addressing social and spiritual problems as part of their role while 50% of private doctors viewed social problems as part of their role. Only a third of private doctors viewed discussing and treating spiritual problems as part of their role.

This result ties in with the observation and evidence in the literature that medicine mainly focuses on the disease and not on the person as a whole. Palliative care provides holistic care that envelope all aspects of physical, psychological, social and spiritual care that is needed by patients.²¹ Time constraints in practice as well as possible patient possible reservations about or hesitancy to volunteer information on social and spiritual needs might contribute to not addressing these needs of patients. This highlights the need for education and training of health care workers to equip them with skills to address the needs, especially the spiritual needs of their patients.

BELIEFS

Only 57% of state doctors and 33.3% of private doctors were comfortable in treating their patient's pain all of the time, while 66% of private doctors and 33% of state doctors were comfortable in treating their patient's pain most of the time. Possible reasons may include the following: In an academic state hospital the lateral support system for doctors from other specialties is readily available and interdepartmental referrals are done readily. By referral and consultation to other specialties oncology doctors are exposed to expertise that they can draw on and the new knowledge can be used for future patients. It is important to note that treatment in the state is covered at a global fee while private patients have to pay fee for service. Financial implications may influence referrals to other specialists in private. Further possible reasons may be that doctors often do not thorough lyassess pain due to lack of knowledge or time constraints. Some of the barriers to pain relief are poor assessment and the lack of knowledge or lack of applying knowledge to treat pain effectively.

These results concur with the result of question 11 where only 28.1% of all doctors stated that they had good training in treating pain. However, all doctors should be trained and skilled in pain management and this need may be addressed by improving undergraduate training as well as continued medical education or workshops.

The majority of doctors (92% state and 100% private) felt they did their best in providing the best possible treatment when a patient reached the point where cure is no longer an option. Only one (7.7%) of state doctors felt that he/she failed the patient when cure was no longer an option. One state doctor (7.7%) wrote in the answer “none of the above”. This raises the question if doctors at times may be ignoring their own feelings when treating patients. This may be a coping strategy due to the lack of emotional support for doctors dealing with dying patients. Oncology units, clinics and hospitals should have support programs in place to assist staff in dealing with the demands of their jobs and to prevent burnout.

Eighty five percent of the state doctors and 22.3% of private doctors chose the option that hospice is not available in their area or not accessible for the patients as a reason for non-referral.

There are six hospices in the City of Cape Town Health District that are members of the Hospice Palliative Care Association. These hospices provide services to 3.4 million people (2007) in an area of 2461 km². There are a total of 16 member hospices serving the whole of the Western Cape Province, covering an area of 129 386 km² with a population of more than 5.2 million.¹³³

Both groups of doctors accept referrals from the whole of the Western Cape and it is interesting to note that state oncology patients from the Western Cape Province are referred to only two academic hospitals in Cape Town that provide oncology services. These patients are mostly dependent on public transport to get to health care services and financial constraints are a major stumbling block for them. It is important to draw the doctors' attention to the fact that palliative care and hospice services can be offered to the patient in his own home.

The majority of doctors (64% of state doctors and 83.3% of private doctors) stated that patients are resistant to referral to hospice. The possible reasons are explored discussed in the next paragraph. Fifty percent of private oncologists and 35.7% of state doctors said that the patient's family refuses referral to hospice.

Reported resistance to referral by patient and family is twenty percent higher in private practice than among state patients.

It was stated by responders that palliative care facilities are not easily accessible to the majority of patients in the Western Cape. However it is important to draw the attention of doctors to the fact that palliative care is administered to patients in their own homes by hospice staff. It is clear that more needs to be done to promote palliative care in the communities and health care facilities, by training staff and educating patients about what palliative care services are available. Both HPCA development strategy and the Western Cape DoHPalliative care initiatives are addressing the need, however even more should be done to make palliative care available to all people in rural areas.

The majority of doctors, in fact 100% of the private doctors and 92.9% of state doctors thought the main reason for resistance to referral to hospice was the perception of the patient that hospice means end of life. Twenty eight percent of state doctors and 16.8% of private oncologists thought fear of the unknown was the main reason for resistance to referral. Sixteen percent of private oncologists stated the perception of the doctor that he/she is giving up on the patient, was a reason for patient resistance to referral.

This result again shows the need for more education of health care providers, both undergraduate and post graduate as well as the public and communities about what palliative care is, what services are offered at palliative care centres or hospices and how this service can positively impact on the patients disease progression. Even when information is available many people choose not to read information about hospice because of preconceived ideas. In doing so, they choose not to access available information that may help them to care for patients with limited life expectancy.

At present HPCA is running the Power of 10 program which is providing a platform for word-of-mouth marketing and creating positive perceptions for hospice care in South Africa.¹³⁴

All the state doctors and 94.4% of private doctors believe that the patient should decide on the place of death and a further 42.9% of state doctors and 50% of private oncologists believe that the family should decide on the place of death. Taking patient autonomy into account it should ultimately be the patient who decides where he/she would like to die. The palliative care team can facilitate discussion between the patient, family members and the primary carer to make a joint decision or to explain the patient's wishes to the family. A care plan which is sensitive to the patient's culture and beliefs should be set up and communicated clearly to all, making provision for possible eventualities in order to honour the patient's wishes.

Despite more than 40 years of specialist palliative care in the United Kingdom, the place of death is still not where the patient wants it. Most people express the preference for a home death when asked where they would like to die. However, according to Higginson, only 26% achieve this goal.¹³⁵ Palliative care is less developed in South Africa than in the UK and we do not have accurate figures for place of death vs. desired place of death. However the figure would be expected to be much lower than in the UK.

PRACTICE

From the results it seems that the WHO guidelines are still being used by many of the doctors working in oncology in the City of Cape Town Health District.¹²⁹ This is in keeping with results of other questions and implies that pain management is adequate.

The majority of doctors find it easy to communicate and give full information about disease progression to the patient. Fifty seven percent of state doctors and 33.3% of private oncologists first discover what the patient wants to know and share the relevant information. Fourteen percent of state doctors felt it was not easy to communicate information about disease progression as telling the patient the disease is not curable takes away the patients hope.

This last result is contrary to what was found in the literature. Improving communication skills may be very helpful for doctors working in oncology.

A 100% of private oncologists and 85% of state doctors answered that they feel comfortable to discuss death and dying with their patients when cure is no longer the aim of treatment. According to the results the majority of doctors working in oncology are comfortable in discussing disease progression and end-of-life issues when cure is no longer an option. A survey amongst patients on their experience of the doctors' communication style and the level of patient understanding would confirm these findings.

In the reviewed literature it has been shown that patients prefer to have information and that it helps them prepare for their future. Great care must be taken to communicate clearly to avoid ambiguous language and to check the patient's understanding²⁹. Honest and good communication is essential in building a trusting doctor-patient relationship. Fallowfield reported that a good relationship with the doctor helped patients to cope with information.²⁹ Benefits to the patient include the patient having the confidence to discuss difficult issues with the doctor. Knowing and understanding the reality of the condition gives the patient the opportunity to plan his future realistically by enhancing realistic hope. Good communication prevents false hope and the need to explore inappropriate treatment options or wanting futile treatment. Communication skills training should form an essential part of undergraduate and postgraduate training of doctors.

A hundred percent of state doctors and 66.7% of private oncologists refer the patient to hospice for treatment when cure is no longer the option. This result demonstrates again the late referral of patients to hospice. Ninety four percent of private oncologists and 78.4% of state doctor continue to treat the patient to the best of their ability. Thirty nine percent of private oncologists and 28.6% of state oncology doctors refer the patient to a palliative care team.

It seems as if private doctors may continue to treat the patient for longer than state doctors. This may be due to the perception that referral of a patient means failing or abandoning the patient while other reasons may include financial incentives to keep treating the patient. Other reasons may include the lack of confidence of doctors in hospice services or doctors might have difficulty in discontinuing aggressive treatment. Again improved communication skills regarding breaking bad news might be helpful to the doctors. Improved cooperation between referring doctors and hospice may be able to address misconceptions about services and service levels.

The younger doctors in the state may have had more exposure to or training in palliative care than the older doctors in private practice.

The opportunity to take part in an elective program at St Luke's hospice has been available to medical students for about 20 years and palliative care has formed part of the undergraduate training at University of Cape Town since 2004. None of the doctors that took part in the survey however had palliative care as part of their formal undergraduate training. Palliative care training has increased in recent years but it is still not an integral part of undergraduate medical school curricula throughout South Africa. Training programs need to be developed further and extended to include nursing and other disciplines.

Sixty four percent of state oncology doctors and only 16.7 % of private oncologists refer the patient back to the GP or primary clinic. The reason for this result is not clear but in many cases the primary clinic is the only option for the care of rural patients. State facilities have protocols for treatment of cancer and once the patient has exhausted treatment options the patient is referred back to the primary clinic for further symptomatic treatment. Barnard demonstrated improved palliative care outcomes if the family physician or GP is included in all stages of care of the patient. The GP is the one doctor that is familiar with the circumstances of the patient, including the personal history and the family background.

This doctor is often excluded from continued care of the patient by marginalization by the treating specialists.²⁴ Again, improved and effective communication between the treating doctors and referring doctors will be beneficial to the patient.

Sixty four percent of state oncology doctors and 38.8% of private oncologists always refer patients with progressive incurable disease to hospice. This was a significant difference in practice between state and private doctors. Forty three percent of state oncology doctors and 72.2% of private oncologists refer the patient to hospice if it is the patient's choice. It is not clear whether the doctor will revisit the patient's decision to decline referral to hospice at a later stage. It is important to address patient barriers towards referral to hospice by empowering patients with knowledge regarding palliative care and the benefits thereof for the patient and family. Communication in practice can be time consuming. It is therefore important to have strategies in place that will assist patients in obtaining more information and the patient needs to be aware that his or her decision regarding deferral of hospice referral is reversible.

The average patient in private practice in South Africa is from a higher socio-economic status and has a higher education level than the average state patient. These patients may question referrals and treatment plans more than the state patients. If a patient declines referral to hospice the doctor has to respect patient autonomy although further discussion is indicated. It is clear from the results that hospice referral is not an automatic step in the treatment plan of oncology patients. This may be due to factors like administration, lack of availability of hospice, lack of good communication between hospice and the treating doctor, a lack of knowledge regarding services offered by hospice, a lack of experience with hospice and palliative care and the benefits thereof. This lack of knowledge can be addressed by further education of doctors including continued professional development programmes. Hospices should also be involved in educating doctors and staff members regarding available services and by providing regular feedback on the progress of referred patients.

Ninety three percent of hospital oncology doctors and 100% of the private oncologists refer the patient to a social worker. It is unclear why the discrepancy came up in the results as the state oncology department has dedicated social workers for the patients. The social worker's main function is counseling but she can assist the patient with applying for child care grants and housing, assist with the drawing up of a will, care planning for children in the house, and memory work. The one large private oncology group practice also has social workers on their staff. Independent oncologists work in collaboration with private social workers.

Sixty four percent of state oncology doctors and 50% of private oncologists refer the patient to a spiritual counselor or religious worker. This is a statistically significant difference and may be due to the fact that state doctors may be more aware of their own spirituality. From this it is clear that the spiritual needs of patients may not be met. Doctors should pay special attention to enable the patient to discuss specific needs. Fifty percent of state oncology doctors and 66.7 % of private oncologists refer the patient to a psychologist. Fifty seven percent of state oncology doctors and 77.8 % of private oncologists refer the patient to a support group. In the private sector support groups may be more easily accessible to patients. The incidence of referrals to other disciplines was not investigated.

The majority of doctors in state and private discuss the place of death with the patient and the family. However, fourteen percent of state oncology doctors never discuss the place of death with the patient or family.

In general, private oncologists had discussions about the place of death more often than state doctors. It is of concern that 14% of doctors in the state never discuss the place of death. This percentage might actually be higher if a survey amongst patients and families are to be undertaken, as doctors according to the literature reviewed generally seem uncomfortable in discussing decline in prognosis although it was not reflected in the results of this survey.

Only 57.1% of state oncology doctors and 50 % of private oncologists refer patients with disease progression to hospice. This would be the ideal stage to refer a patient to hospice to ensure that the patient and family receive maximum benefit from the referral.

However, the majority of doctors refer patients with end stage disease (meaning cure is no longer an option) and terminally ill patients (undergoing the last stage of the disease according to the Oxford dictionary) to hospice.

Fifty percent of private oncologists refer dying patients to hospice while no state doctor marked this option. These results are concerning as it demonstrate that the majority of patients are being referred to hospice late (end stage disease or terminal ill) or very late (dying) in the trajectory of their disease, thus limiting the benefit that the patient and the family can draw from comprehensive palliative care as also described in the literature.^{26,28}

At least 50% of doctors recognized that there is added benefit in referring patients earlier to hospice, namely at the time of disease progression. Hospice should endeavor to extend the knowledge and the positive experience of working with the hospice team to more doctors.

Regular communication with the referring doctor is key to keep him/her informed on the condition and treatment of the patient, as well as to serve to remind the doctor what services are available at hospice. This will prevent the doctor to feel marginalised. A positive experience for the doctor and patient will facilitate future referrals.

The palliative care needs of paediatric patients should be addressed as a matter of urgency. The majority of hospices at present do not accept children into the program. Palliative care programs should be adapted to be able to accommodate the increasing number of children that will need the service in future.

In South Africa the cultural diversity of our nation poses even further challenges to implementing a nationwide easily accessible and user friendly palliative care service. It is not clear from the results whether the misconceptions about palliative care and hospice services are due to a failing of the palliative care community in not describing the discipline clearly enough or a result of the complexity of the discipline.

Limitations of the study

General

Studying and doing research part time has been a challenge in many ways. However it was an invaluable learning experience.

Data collection

Although the sample size was small the percentages of eligible respondents were high and the response rate was excellent.

A self-administered questionnaire was used in this survey. It would have been valuable to have had a field worker to explain the questionnaire to participants to rule out any misconceptions. However due to time, organizational and financial constraints a field worker could not be used.

Questionnaire

This questionnaire was set up by the researcher using the questionnaire by Fakrodeen as a guideline.¹²³ Well tested and validated tools that are available should be used for future research. Despite piloting the questionnaire some questions unfortunately still contained some ambiguity and that made interpretation of the results difficult. The fact that more than one answer could be marked also led to getting more possible answers than respondents, making the results more difficult to interpret. However, being able to choose more than one answer gave the respondents more opportunity to express their views and gave the researcher more information. One doctor still felt the need to put a response in writing as the available options did not cover his response.

However, in question 12 this helped to point out that the vast majority of doctors saw discussing and treating physical and psychological problems arising from cancer as their role.

Where possible answers were set and an “all of the above” option was given it skewed the results in that doctors ticked individual answers plus the “all of the above” option. “All of the above” should have been included only in a questionnaire where only one answer may be ticked.

Despite limitations in this study it was still a rewarding process for the researcher.

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Chapter 7

CONCLUSION AND RECOMMENDATIONS

A descriptive KABP survey was done in the City of Cape Town Health District to identify possible barriers and other factors that influence the referral of patient to hospice by oncologists. A self-administered anonymous questionnaire was used to explore the knowledge, attitude, belief and practice of doctors working in oncology.

The majority of all doctors who took part in the survey answered the knowledge and attitude questions correctly but it was interesting to see that nearly half of the doctors did not view discussing and treating social and spiritual problems as part of their role as oncologists. The results of the belief questions rendered expected results but less than half of the doctors felt comfortable in treating pain all the time. The majority of doctors chose the correct answers in the practice questions. However, the results showed that although referral to hospice takes place, the referral for the majority of patients were late or very late.

Factors that influenced referral of patients to hospice included lack of training of oncologists in palliative care, the view of the oncologist's individual role in the care of his patients as well as the ability to communicate comfortably with patients regarding end-of-life care.

The doctors working in oncology were knowledgeable about the services offered by hospice although fewer doctors knew that spiritual care was being offered by hospice. Barriers to referral to hospice that were identified included a lack of training of the doctor in care for the dying, the perception of the doctor that hospice referral means giving up on the patient and difficulty in communication regarding end-of-life care.

Doctors stated that reasons for non-referral to hospice included amongst other that hospice is not available in area or not accessible to patients, the perception of the doctor that he/she is giving up on the patient, previous dissatisfaction with service by hospice and not wanting to lose control of the treatment of the patient. The referring doctor should play an important part in the palliative care team.

Patient factors included patient resistance to referral, the perception of the patient that referral to hospice means loss of hope, fear of the unknown, the patient's perception that hospice means end of life and bad memories from the patient's perspective if the patient had lost a family member

In the interest of patients, late timing of referral to hospice should be addressed by improving the training of all doctors and clinic staff to identify patients early who qualify for hospice or palliative care referral. Palliative care centres and hospice should be accessible in the community, even in rural areas. It is important to remember that palliative care is mostly delivered to the patient in his own home. Hospices and palliative care centres should also advocate for early referral and be involved in informing doctors and the public of the services that are available in the area. Information may be available in the community but is not accessed by the community. Therefor the ideal would be to implement different types of communication like printed matter, electronic newsletters, newspapers or magazines or brochures or the performing arts for both doctors and the public.

The aims and objectives of this study have been met. Factors that influence the referral of patients have been identified, perceptions of oncologists have been explored and a number of possible barriers to referral have been identified. It has also been identified that patients are referred late to palliative care in the Western Cape and a strategy to address this needs to be developed.

RECOMMENDATIONS

Palliative care should be integrated in undergraduate curriculum of medical students as well as nursing and associated disciplines. This will facilitate better understanding of palliative care. Education should continue with Continued Professional Development

programs as well as integrating palliative care training into postgraduate curricula of oncologists and other specialties.

Palliative care should be available to all patients in all areas. This can be achieved by training all staff in existing clinics and communities in the principles and practice of palliative care.

Hospices should market themselves to doctors and case managers of hospitals to promote cost effective treatment for all patients. Administrative barriers should be reduced by making referral forms and processes easy to follow and uniform. Hospices should be more visible in the community and information or talks by the hospice staff regarding available services should be communicated to doctors and the community. Misconceptions about hospice should be addressed.

The primary health care provider of GP should be more involved in the care of the patient. The hospice or palliative care team should work in close collaboration with the referring doctor and communication between these parties should be excellent. The referring doctor should not be concerned that he or she will lose the patient or be marginalised by hospice.

A large number of doctors who have the opportunity to discuss hospice and palliative care with their patients are choosing not to do so. The reason for this perception poses the opportunity for further investigation.

Patients should be referred to palliative care services early in the disease process and oncologists should work as part of the palliative care team providing care to oncology patients.

Advocacy for early referral should include all doctors and nursing staff, especially the oncologists and general practitioners.

APPENDIX

List of documents in appendix

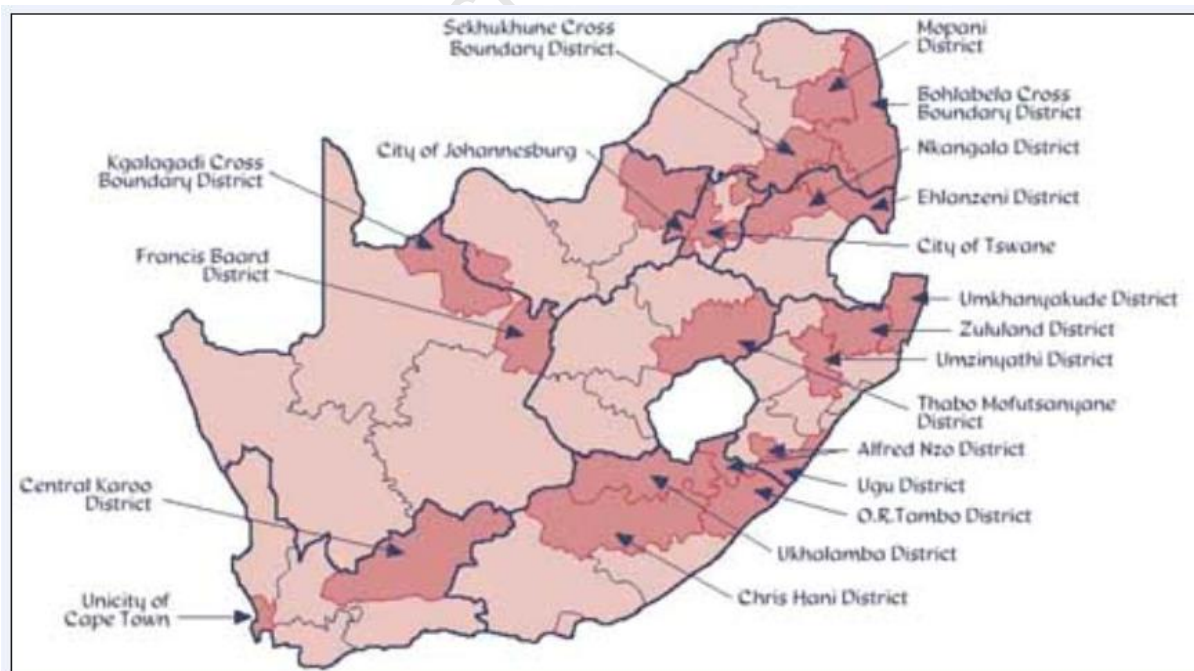
1. Map of Provinces of South Africa
 Map of Health Districts
 Map of City of Cape Town Health District
2. Letter to Oncologist
 Brief aan Onkoloog
3. Questionnaire
4. Ethics Approval
5. SPIKES Protocol for breaking bad news
6. Useful language for Hospice Discussions
7. The ECOG Scale of Performance Status
8. Karnofsky Performance Status Scale
9. Calculations of Fisher Exact test

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APPENDIX 1



Provinces of South Africa



Health Districts of South Africa



City of Cape Town Health district

APPENDIX 2
Letter to Oncology Department and Oncology Practices

2 Franshoek Rd
Durbanville
7550

Date

Dear Doctor

I am undertaking a research study for MPhil Palliative care.

The aim of the study is to evaluate possible factors that contribute to late referral of cancer patients by oncologists to hospice services in the Western Cape.

I would like to invite you to take part in the survey which is undertaken by means of a questionnaire. The questionnaire is anonymous and confidential.

An application for approval by the Ethics Committee of the University of Cape Town has been submitted. (A copy of approval will be attached).

All respondents will receive a report on the results of the study.

I thank you for your participation.

Yours sincerely

Dr Teresa Swart
(082 9206734)

Brief aan Onkoloog

2 Franshoekweg

Durbanville

7550

Datum

Geagte Dokter

Ek is tans besig met navorsing vir my skripsie vir MPhil. Palliative Care by UCT.

Die onderwerp van my navorsing is die evaluasie van moontlike faktore wat kan bydra tot die laat verwysing van onkologie pasiente na hospices in die Wes Kaap.

Ek nooi u graag uit om deel te neem aan die studie wat met behulp van 'n vraelys gedoen word.

Die vraelys is anonym en die inligting wat verskaf word is vertroulik.

Ek het godkeuring vir die studie verkry van die Research Ethics Committee van UCT (REC REF:256/2006).

Alle deelnemers sal 'n verslag oor die uitslag van die studie kry.

By voorbaat dank

Teresa Swart

0829206734

APPENDIX 3

QUESTIONNAIRE

Demographics

Age

Gender: Male Female

Suburb.....

Year qualified MBChB or equivalent.....

Year qualified as specialist.....

Type of specialist.....eg oncologist, radiation oncologist, medical oncologist, internist etc

Number of years experience in oncology as trainee/registrar.....

Years experience as specialist.....

Years experience as medical officer in oncology.....

Type of practice:

- ☐ Private practice: solo practice
- ☐ Private practice: group practice
- ☐ Public sector
- ☐ Combination of public and private sector

ONE OR MORE ANSWERS CAN BE TICKED

1. Do you feel comfortable in treating your patient's pain?

- ☐ Yes, all the time
- ☐ Most of the time
- ☐ Sometimes
- ☐ No

2. Do you use the WHO step ladder guidelines regularly when prescribing analgesics for cancer pain?

- ☐ Yes, always
- ☐ No, never
- ☐ Sometimes
- ☐ Only in patients with difficult pain

- 3. What pain medication do you usually use to initiate pain control?**
- ☐ Paracetamol
 - ☐ NSAIDS
 - ☐ Morphine
 - ☐ All of the above
- 4. At what stage of disease would you prescribe morphine as an analgesic therapy for treatment of severe pain?**
- ☐ At any time during the course of their cancer
 - ☐ When the prognosis is less than 1 year
 - ☐ When the prognosis is less than 6 months
 - ☐ When the prognosis is less than 3 months
- 5. Pain experienced by cancer patients can be due to the following:**
- ☐ caused by the tumour
 - ☐ complications of cancer
 - ☐ anti cancer treatment
 - ☐ conditions unrelated to cancer
 - ☐ all of the above
- 6. How do you feel in yourself when a patient reaches the point where curing the disease is no longer an option?**
- ☐ I failed the patient
 - ☐ I failed the family
 - ☐ I failed myself
 - ☐ I did my best in providing the best possible treatment
- 7. Do you find it easy to communicate information about disease progression?**
- ☐ Yes, I give full information to the patient
 - ☐ I discover what the patient want to know and share the relevant information with him/her
 - ☐ I give full information to the family, but prefer not to tell the patient everything
 - ☐ Telling the patient the disease is not curable takes away the patient's hope
- 8. Do you feel comfortable discussing end-of-life issues with your patient when cure is no longer the aim of treatment?**
- ☐ Yes, I am comfortable to talk about death and dying to my patients
 - ☐ I refer the patient to a private counsellor
 - ☐ I refer the patient to hospice
 - ☐ I tell the family, but not the patient

9. What do you do with patients when cure is no longer the aim of treatment?

- ☐ I send the patient back to the GP or primary clinic
- ☐ I refer the patient to the hospice
- ☐ I continue treating the patient to the best of my ability
- ☐ I refer the patient to a palliative care team

10. What does referring a patient to a hospice mean to you?

- ☐ Giving up on a patient
- ☐ Choosing professional supportive care
- ☐ Abandoning the patient
- ☐ I work in partnership with a multidisciplinary palliative care team

11. Do you feel your training as an oncologist prepared you well for caring for your dying patient?

- ☐ Yes, I had good training in care of the dying
- ☐ I had good training in treating cancer
- ☐ I had good training in treating pain
- ☐ No, my training focussed on cure only

12. As an oncologist or medical officer in oncology, do you see it as part of your role to discuss and treat your patient's

- ☐ psychological problems arising due to the cancer
- ☐ spiritual issues the patient has
- ☐ social problems
- ☐ physical symptoms e.g. pain
- ☐ none of the above are part of my role

13. Do you refer your patients with progressive, incurable disease to hospice ?

- ☐ Yes, always; it gives the patient and family additional care
- ☐ Yes; if it is the patient's choice
- ☐ Never; the oncology team at the oncology practice or hospital continue to manage the patient
- ☐ Sometimes; if the patient's medical aid or funds are depleted

14. In your opinion as the treating doctor what are the most likely reasons for non- referral of patients to hospice?

- ☐ Referral to hospice means loss of hope for the patient
- ☐ Previous dissatisfaction with service rendered by hospice
- ☐ Hospice is not available in my area or not accessible for the patients
- ☐ Patient is resistant to being referred to hospice
- ☐ You, as a doctor, do not want to lose control of the treatment of the patient
- ☐ Medical aid does not provide benefits for palliative or hospice care
- ☐ The patient's family refuse referral to hospice

15. If you find the patient resistant to referral to the hospice, what do you think is the main reason ?

- ☐ Fear of the unknown
- ☐ Perception of the patient that hospice means the end of life
- ☐ Perception of the doctor that I am giving up on my patient
- ☐ Bad memories from the patient's perspective if the patient had lost a family member
- ☐ Medical aid does not provide benefits for palliative or hospice care

16. Do you ever refer your patient to

- ☐ A social worker
- ☐ A spiritual counsellor/religious worker
- ☐ A psychologist
- ☐ Support group

17. Do you ever discuss the place of death with any or all of the following?

- ☐ the patient
- ☐ the family
- ☐ primary caregiver
- ☐ it is never discussed

18. Who do you believe should decide where a patient would like to die?

- ☐ The doctor
- ☐ The patient
- ☐ The family
- ☐ The primary care giver

19. In your opinion, which combination of carers would be the ideal to care for a patient during the terminal stage?

- ☐ Multidisciplinary palliative care team
- ☐ Oncologist only
- ☐ Oncologist assisted by private home nursing staff
- ☐ Oncologist and hospital staff
- ☐ Oncologist and oncology practice team

20. Private nursing in the patient's home offers:

- ☐ good symptom control
- ☐ physical care
- ☐ spiritual care
- ☐ assistance with activities of daily living
- ☐ care focused on preserving quality of life

21. Services offered by the hospice include:

- ☐ treatment focused on preserving quality of life during disease progression and deterioration of condition
- ☐ active management of distressing symptoms
- ☐ psychosocial support
- ☐ spiritual care

22. What type of patient would you consider to refer to hospice?

- ☐ Terminal ill patients
- ☐ Dying patient
- ☐ Patient with end stage disease
- ☐ Patient with disease progression

23. The most likely explanation that a terminal cancer patient would request an increased dose of pain medication is;

- ☐ the patient is experiencing increased pain
- ☐ the patient's requests are related to addiction
- ☐ the patient is becoming depressed
- ☐ the patient is requesting more staff attention

24. Which of the following drugs are considered useful analgesic adjuvants?

- ☐ Non steroidal anti-inflammatory agents / NSAID
- ☐ Corticosteroids
- ☐ Tricyclic antidepressants
- ☐ All of the above
- ☐ None of the above

25. What do you understand palliative care to be?

- ☐ Pain control and active symptom control
- ☐ Holistic approach
- ☐ Palliative chemotherapy
- ☐ Psychosocial support
- ☐ Support to the family
- ☐ Spiritual care
- ☐ Support system to assist the patient to live as actively as possible



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Telephone [021] 406 6338 • Facsimile [021] 406 3411
e-mail: preawarc@curie.uct.ac.za

18 July 2006

REC REF: 256/2006

Dr. MT Swart
Family Medicine

Dear Dr. Swart:

AN EVALUATION OF FACTORS THAT CONTRIBUTE TO LATE REFERRAL OF CANCER PATIENTS BY ONCOLOGISTS TO HOSPICE SERVICES IN THE WESTERN CAPE

Thank you for submitting your study to the research Ethics committee for review. It is a pleasure to inform you that the committee has approved the above mentioned study.

Please quote the REC. REF in all your correspondence.

Yours sincerely

DR. M BLOCKMAN
CHAIRPERSON

APPENDIX 5

SPIKES Protocol for breaking bad news

Step 1: SETTING UP THE INTERVIEW

Step 2: P- Assessing the patient's PERCEPTION

Step 3: I – obtaining the patient's INVITATION

Step 4: Giving KNOWLEDGE and information to the patient

Step 5: Addressing the patient's EMOTIONS with empathic responses

Step 6: STRATEGY and SUMMARY

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APPENDIX 6

Useful Language for Hospice Discussions ⁵⁸	
Identify other decision makers	<p>“Is there anyone you rely on to help you make important decisions?”</p> <p>“Who in the family should be there with us when we discuss the results?”</p>
Assess understanding of prognosis	<p>“What have your other doctors told you about your condition?”</p> <p>“Have they talked to you about what this latest problem might mean for you?”</p> <p>“From what you know, do you think that over the next month your cancer will get better, worse, or stay the same?”</p>
Define the patient’s goals for care	<p>“What do you hope for most in the next few months?”</p> <p>“Is there anything that you’re afraid of?”</p>

Useful Language for Hospice Discussions (continues)	
Reframe goals	<p>"I wish we could guarantee that we could keep you alive until your daughter's graduation, but unfortunately we can't. Perhaps we can work together on a letter for her to read on that day, so she will know you are there in spirit in case you cannot be there."</p>
Identify needs for care	<p>"It can be very difficult to care for a family member at home, and no one can do it alone. Have you thought about what kinds of help you might need?"</p> <p>"Would it help if we could find a way to deliver your medications to you?"</p> <p>"Would it reassure you if we could send a nurse out to your home to check on you?"</p>
Summarize and link goals with	<p>"So I think I understand that your main goal is to stay at home and spend time with your family.</p> <p>To do that care needs we need to help you in several ways, for instance, by sending a nurse out to your home and giving you both some help around the house. Is that right?"</p>
Introduce hospice	<p>"One of the best ways to give you the help that you will need to stay at home with your family is a program called hospice. Have you heard of hospice?"</p> <p>"Hospice is able to provide more services and support at home than most other home care programs."</p> <p>"The hospice team has a lot of experience caring for seriously ill patients at home."</p> <p>Respond to emotions elicited and provide closure.</p>

Useful Language for Hospice Discussions (continues)	
Acknowledge response	<p>You seemed surprised to learn how sick you are.”</p> <p>“I can see it’s not easy for you to talk about hospice.”</p>
Legitimize reaction	<p>“Many people are understandably upset when they learn how ill their loved one is and that hospice is a possibility.”</p>
Empathize	<p>“I can imagine how hard this is for both of you; you care about each other so much.”</p>
Explore concerns	<p>“Tell me what’s upsetting you the most.”</p>
Explain hospice goals	<p>“Hospice doesn’t help people die sooner. Hospice helps people die naturally, in their own time.”</p> <p>“Hospice helps people live as well as they can for as long as they can.”</p>
Reassure	<p>“Hospice’s goal is to improve your quality of life as much as possible for whatever time you have left.”</p> <p>“Hospice can help you and your family make the most of the time you have left.”</p>
Reinforce commitment to care	<p>“Let’s think this over for a day or two; you know I will continue to care for you whatever decision you make.”</p>
Recommend hospice	<p>“I think that hospice would be your best choice right now, but of course, the final decision is yours.”</p> <p>“Hospice could be very helpful to you in the ways that we’ve talked about, but I realize it’s a big decision. I’d like to arrange for a hospice nurse to visit you so you can decide for yourself whether hospice is right for you”.</p>

APPENDIX 7

The ECOG Scale of Performance Status

The ECOG Scale of Performance Status (PS) is widely used to quantify the functional status of cancer patients, and is an important factor determining prognosis in a number of malignant conditions. The PS describes the status of symptoms and functions with respect to ambulatory status and need for care.

PS 0	Normal activity
PS 1	Symptoms, still nearly fully ambulatory
PS 2	Less than 50% of daytime in bed
PS 3	More than 50% daytime in bed
PS 4	Completely bedridden

APPENDIX 8

Karnofsky Performance Status scale ⁹⁷

100%	Normal, no complaints; no evidence of disease
90%	Able to carry on normal activity; minor signs or symptoms of disease
80%	Normal activity with effort; some signs or symptoms of disease
70%	Cares for self; unable to carry on normal activity or to do active work
60%	Requires occasional assistance, but is able to care for most of his personal needs
50%	Requires considerable assistance and frequent medical care
40%	Disabled; requires special care and assistance
30%	Severely disabled; hospital admission is indicated although death not imminent
20%	Very sick; hospital admission necessary; active supportive treatment necessary
10%	Moribund; fatal processes progressing rapidly
0%	Dead

APPENDIX 9

Calculations Fisher exact test

KNOWLEDGE

Question 3

Initiating pain control	State	Private
Paracetamol	9	11
Other	5	7
Total	14	18

(p=1.00000, Fisher exact test)

Question 5

Cause of pain	State	Private
All of above	14	15
Other	0	3
Total	14	18

(p=1.00000, Fisher exact test)

Question 20

Benefits of private nursing	State	Private
Spiritual	5	4
Other	9	14
Total	14	18

(p=0.453315, Fisher exact test)

Question 21

Hospice services	State	Private
Focused on QOL	14	16
Other	0	2
Total	14	18

(p = 0.491935, Fisher exact test)

Question 24

Analgesic adjuvant	State	Private
All of the above	10	18
Other	4	0
Total	14	18

(p = 0.027836, Fisher exact test)

Question 25

Understanding of PC	State	Private
Psychosocial support	6	16
Other	8	2
Total	14	18

(p = 0.008374, Fisher exact test)

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ATTITUDE

Question 4

Morphine for pain control	State	Private
Any time	14	18
Other	0	0
Total	14	18

Question 10

Meaning of hospice	State	Private
Supportive care	11	9
Other	3	9
Total	14	18

($p = 0.146711$, Fisher exact test)

Question 11

Oncology training	State	Private
Care for dying	0	10
Other	14	8
Total	14	18

($p = 0.001252$, Fisher exact test)

Question 11

Oncology Training	State	Private
Focused on cure	9	4
Other	5	14
Total	14	18

($p = 0.029262$, Fisher exact test)

Question 12

Role of oncologist	State	Private
Psychological problems	10	17
Other	4	1
Total	14	18

(p = 0.141963, Fisher exact test)

Role of oncologist	State	Private
Spiritual issues	8	6
Other	6	12
Total	14	18

(p = 0.283121, Fisher exact test)

Question 19

Care in terminal phase	State	Private
Multidisciplinary team	14	18
Other	0	0
Total	14	18

Question 23

Increased dose of analgesics	State	Private
Increased pain	14	18
Other	0	0
Total	0	0

BELIEF

Question 1

Comfortable in treating pain	State	Private
All the time	8	6
Other	6	12
Total	14	18

($p = 0.0283121$, Fisher exact test)

Comfortable in treating pain	State	Private
Most of the time	5	12
Other	9	6
Total	14	18

($p = 0.152669$, Fisher exact test)

Question 6

Feelings when cure is not an option	State	Private
I did my best	13	18
Other	1	0
Total	14	18

($p = 0.437500$, Fisher exact test)

Question 14

Reason for non-referral	State	Private
Not accessible for pt	12	4
Other	2	14
Total	14	18

($p = 0.000965$, Fisher exact test)

Question 14

Reasons for non-referral	State	Private
Patient resistance	9	15
Other	5	3
Total	14	18

($p = 0.251672$, Fisher exact test)

Question 15

Reason for patient resistance	State	Private
Patient perception	13	18
Other	1	0
Total	14	18

($p = 0.437500$, Fisher exact test)

Reason for patient resistance	State	Private
Pt bad memories	1	4
Other	13	14
Total	14	18

($p = 0.354700$, Fisher exact test)

Question 18

Place of death	State	Private
Patient decide	14	17
Other	0	1
Total	14	18

($p = 1.000000$, Fisher exact test)

PRACTICE

Question 2

Use of WHO guidelines	State	Private
Always	8	6
Other	6	12
Total	14	18

($p = 0.283121$, Fisher exact test)

Question 7

Ease of communication about disease progression	State	Private
Full info to patient	10	13
Other	4	5
Total	14	18

($p = 1.000000$, Fisher exact test)

Question 8

Comfortable discussing end-of-life issues	State	Private
Discuss death and dying	12	18
Other	2	0
Total	14	18

($p = 0.183468$, Fisher exact test)

Question 9

Further treatment	State	Private
Refer to GP	9	3
Other	5	15
Total	14	18

($p = 0.009998$, Fisher exact test)

Further treatment	State	Private
Refer to hospice	14	12
Other	0	6
Total	14	18

(p = 0.023800, Fisher exact test)

Question 13

Referral to hospice	State	Private
Yes, always	9	7
Other	5	11
Total	14	18

(p = 0.285163, Fisher exact test)

Referral to hospice	State	Private
Yes if pt choice	6	13
Other	8	5
Total	14	18

(p = 0.149183, Fisher exact test)

Question 16

Referral to other disciplines	State	Private
Spiritual counselor	9	9
Other	5	9
Total	14	18

(p = 0.489590, Fisher exact test)

Question 17

Discussion about place of death	State	Private
Patient should decide	10	17
Other	4	1
Total	14	18

($p = 0.141963$, Fisher exact test)

Discussion about place of death	State	Private
Family	8	16
Other	6	2
Total	14	18

($p = 0.096359$, Fisher exact test)

Question 22

Timing of referral to hospice	State	Private
Terminal ill	9	11
Other	5	7
Total	14	18

($p = 1.000000$, Fisher exact test)

Timing of referral to hospice	State	Private
Dying patient	0	9
Other	14	9
Total	14	18

($p = 0.001805$, Fisher exact test)

Timing of referral to hospice	State	Private
End stage disease	11	16
Other	3	2
Total	14	18

($p = 0.631257$, Fisher exact test)

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